



INVESTING IN A SYSTEM OF CARE:

FOCUS GROUP INTERVIEWS WITH FAMILIES AND CONSUMERS OF SERVICES FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

Prepared for the Division of Developmental Disabilities
Aging and Disability Services Administration
Department of Social and Health Services

May 2010

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ACKNOWLEDGEMENTS

Thank you to all of the people who took time from their busy days and evenings to talk to me about their lives. From young mothers with babies and toddlers to parents in their senior years, and individuals with developmental disabilities, you all had a unique story to tell. Thank you for your frankness and honesty. Some stories were hard to hear as many of you have had negative experiences in one way or another. Thank you for coming to the Family/Consumer Focus Groups and telling the Division of Developmental Disabilities (DDD) what's working, what could be different, and what you would like for the future.

Also, thank you to all the DDD staff who worked so hard to encourage people to attend the focus group meetings. You did a great job.

Gaye Jensen
Focus Group Program Manager

EXECUTIVE SUMMARY

The purpose of the Focus Group Project was to hear directly from parents, families, and consumers about what is needed to add to the community “system of care” to support children and adults with developmental disabilities. The Division of Developmental Disabilities (DDD) conducted twelve focus groups across the state, with a total of 101 people interviewed representing 70 clients of DDD. Each group was asked to discuss the following questions:

- What services does your family member currently receive?
- What is working well for your family member?
- Is there anything you wish was different or could be changed?
- What does it take for you to trust that community programs can support your child?
- How could institution workers help people in the community?
- Looking into the future, if you could have three wishes for your son/daughter/relative, what would they be?
- Wrap-up: Is there anything else you would like to add to our discussion today?

For community families and self-advocates, several themes stood out:

- Navigating the system and becoming knowledgeable about practical issues, such as guardianship, is a challenge. Families of school age children feel dependent on their school district for information and “don’t know what they don’t know.” Even though there are materials available, from DDD as well as various advocacy groups, the information is not reaching the average person/family.
- Medicaid personal care and respite are critical for many families, especially single parents and families without relatives nearby. Are there ways to help certain families with more hours where the need is extremely critical? Is there a way to provide safe, quality out-of-home respite for families that need a vacation or time away that will help them manage for the rest of the year?
- More training for families and teachers about autism is needed - what are best practices, how do parents manage with children who need routines that are not easy for a family to follow? How can the community be more educated about children with autism and the problems that families face raising a child with unique social and learning needs?
- There are still barriers and problems with using public transportation for people with disabilities - it needs to be easier for them to be a part of their communities.

- The issues of high turnover of staff in community programs and better staff training are concerns to families and consumers with disabilities who want to be able to trust in community programs.
- Families need help addressing the “what happens after I’m gone” question.

Themes from the Residential Habilitation Center (RHC) focus groups included recognizing that:

- A safe environment and well trained staff with little turnover are critical factors for families who are happy with their family member living in an institution.
- Some people with developmental disabilities need more staffing and medical/behavioral support than the typical community program can provide with current resources, and the RHCs can meet those needs.
- The institutions are a home to the people who live there and shouldn’t be thought of as something less.
- Some families do want their children to move back to the community and are frustrated by the lack of community resources and options to meet their child’s needs.

Conclusion

The Division of Developmental Disabilities currently provides supports to approximately 24,000 people living in the community and 915 clients living in RHCs (December 2009). There are approximately 38,000 Washington residents with a qualifying disability, which means that the current system of supports reaches only 63% of eligible clients. Clearly, the system of care for people with developmental disabilities relies on and shares responsibility with many individuals and families.

What can DDD do?

- Improve training and technical assistance efforts so that people with disabilities and their families build trust in their community service system.
- Continue to build a system of supports for people with developmental disabilities that will meet more of the significant and growing unmet needs of families and consumers, including:
 - Strengthening respite, both in-home and out-of home, and Medicaid Personal Care services;
 - Providing behavioral and medication management supports; and
 - Working with school districts to educate families about services and answer their basic questions.
- Develop a cost effective, efficient strategy to make information more readily accessible to families and advocates.

- Take the lead on initiating a joint effort with the Office of Superintendent of Public Instruction (OSPI) to identify best practices and options for working with individuals with autism spectrum disorders.
- Continue to support consumers with developmental disabilities to live in, contribute to, and participate in their communities as much as possible, including employment.
- Influence, whenever possible, transportation options for individuals with disabilities.
- Examine the options for sharing the resources and expertise of the RHCs with community families and clients.
- Address the issue of staff turnover that is of concern to families and clients alike.
- Make the necessary investments in community supports that Governor Gregoire outlined in her policy statement, *Reforming How We Care for Washingtonians with Developmental Disabilities*.

INTRODUCTION

The purpose of the Focus Group Project was to hear directly from parents, families, and consumers about what is needed to add to the community “system of care” to support children and adults with developmental disabilities. To discern from the families’ points of view what is important to them, the Division of Developmental Disabilities (DDD) conducted a series of focus group discussions to explore the depth and nuances of opinion regarding what the service system would have to look like to improve supports to children and adults with developmental disabilities in their homes and/or communities.

We conducted twelve focus groups across the state, with a total of 101 people interviewed: 89 focus group members representing 70 DDD clients and 12 persons with developmental disabilities living in the community and advocating for themselves. Detailed notes from the focus groups are in the Appendix.

Focus Group Questions

Each group was asked to discuss the following questions:

1. What services does your family member currently receive?
2. What is working well for your family member?
3. Is there anything you wish was different or could be changed?
4. What does it take for you to trust that community programs can support your child?
5. How could institution workers help people in the community?
6. Looking into the future, if you could have three wishes for your son/daughter/relative, what would they be?
7. Wrap-up: Is there anything else you would like to add to our discussion today?

The goal was to elicit thoughts and ideas from the group, rather than narrowing choices to yes/no or providing too much information as to be leading the participant in a certain direction.

FINDINGS

A total of 101 people attended the twelve focus groups. Family members were typically parents and a few were siblings.

Number of Focus Groups	Number of Participants	%	Number of DDD Clients Represented
Fircrest School	14		9
Rainier School	10		6
Lakeland Village	15		8
RHC Total	39	38.6%	23
7 Community	50	49.5%	47
2 Self-Advocates	12	11.9%	*
12 focus Groups	101 Participants	100%	70 Clients

*Although DDD clients, these consumers/self-advocates were speaking for themselves.

QUESTION 1: WHAT SERVICES DOES YOUR FAMILY MEMBER CURRENTLY RECEIVE?

This question was more of a “warm-up” question than an expectation of an exact list of services which could be determined from the client information system. The purpose was aimed more at learning what families perceive as a service. For example, 30 of the 50 (60%) community family members mentioned Supplemental Security Income (SSI) or Social Security benefits received by their family member as a valuable “service” which adds to the family income and provides access to medical care through medical coupons.

Other services mentioned by community participants included early childhood services; therapies, such as occupational therapy and physical therapy; special education services at school, including the extended school year for older students; Medicaid Personal Care (MPC), respite, vocational services and adult day health, transportation, recreation, and case management. Five families have sons and daughters receiving services from DDD contracted residential programs, and six self-advocates reported that they also live in supported living or adult family homes.

For RHC families, in addition to noting that the institutions offer everything they could want in a safe environment, there were two primary services that stood out for them. Nineteen of the 39 RHC participants (49%) specifically mentioned medication management/medical care and 12 (31%) specifically mentioned behavior support. As one parent put it, the RHC “has provided better control of our daughter’s medications - a skilled attack on her medical needs.” For the families from Fircrest and Rainier School only, 59% mentioned medication/medical care, and 38% mentioned behavioral support.

QUESTIONS 2 AND 3: WHAT IS WORKING WELL FOR YOUR FAMILY MEMBER AND WHAT COULD BE DIFFERENT OR BETTER?

Families with children/adults living at home:

- ❖ A typical reply to the question of what is working well was, “What is working well is that I have them.” For most people, the answer to Question 2 about what is working tended to be the same answer to Question 1 about services received. In other words, even if it isn’t enough, what they have is a good thing and they are grateful to have it.
- ❖ For the young families with toddlers, having therapies at home and MPC makes a difference. This group was frustrated with budget cuts and waiting lists. This group is most worried about learning what they need to know to help their children as they transition to public school. One mom, who was happy with her current services, was concerned that her child would be segregated from typically developing children in school because of her disability and treated differently.
- ❖ For the families of children ages 4 to 11, several families were very pleased with their child’s school programs. Five families in this group noted that MPC is “a big help.” On the other hand, there was a concern in the group about the lack of training for care providers and that they are not ready to provide care when they arrive, particularly if the child has autism. Several also noted that some teachers need more training to teach and work with children with difficult behaviors. For single mothers in this age group, more MPC hours and more respite hours are very much needed.
- ❖ For the students group, ages 12 to 17, the main “service,” as would be expected, is the school program which seemed to be working well for all but one parent, although it was also noted that teachers need more training about autism. One single mother, whose daughter is medically fragile and has intensive medical issues, said that “without the MPC hours, I wouldn’t be able to have her home.” She also needed more hours to manage, especially as her daughter receives limited schooling hours at home. This group seemed to be the age where families begin to think more about the future. One father said that he would like to see DDD create a “road map” as he didn’t know what his family might qualify for and where to start. Another asked, “What is out there for her (daughter) when they turn 21?”
- ❖ The initial test group was composed of family member of teenagers and young adults. These families were very appreciative of the extra income provided by SSI or Social Security benefits, plus the help of health care funded by Medicaid. Respite and MPC were high on their list of what works, as well as the transitional programs at their children’s high schools. One parent remarked that, “Our household has many different needs and MPC is the number one thing that helps the family stay together.” In terms of what could be better or different, these families want a better way to access information about the service system. They felt that they were dependent on the school district and that some were probably better than others at informing parents. They expressed concern about the future, what will happen to their children when they are gone, and the challenges their children face in making

friends and sustaining genuine friendships. There was concern as well about how to nurture siblings and find appropriate respite resources.

- ❖ Families with children ages 18 to 30 living at home were happy in general with their services, especially job coaches for their sons and daughters with employment. Three parents also rely on respite services which one parent said have been a “lifesaver” and “has saved our family.” This group was also concerned, as the group above, with the flow of information and how a parent moves from birth on through the adult service system which they see as complicated. Another parent asked, “What is the order of everything?” and “When do you do guardianship?” For the parents whose children are still in school, they are worried about whether they can continue working after their child is through school or will they need to stay home. One parent summed it up when he said, “We need to be ready for the future and we are not.”
- ❖ There were two focus groups of families with adult children over 31 years of age, one on the west side of the state and the other on the east side. In the first group, over half lived in DDD contracted residential programs which were working well overall. For them, what could be better would be less staff turnover, better salaries and benefits for residential staff and a lot more training. One family mentioned that their son had lived previously in an RHC and that it would be easier for them if he still did, but that he likes where he lives now and is happy. In the second group, participants expressed gratefulness for the work their case managers have done to help them with services. On the other hand, there was frustration with changing case managers too often and with transitioning to the adult world after school is over. Parents don’t understand the waivers and how to qualify for them. They also feel that resources are not spread out evenly, with many dollars focused on serving a fewer amount of people in institutional settings.

Self-advocates with developmental disabilities living in the community:

- ❖ For consumers with disabilities, having a job and/or living in their own place was very important. All but two of the people in the Tacoma group received services from either an adult family home or supported living in their own home. The others either lived in their own home without services or with a family member. Both groups identified the same two issues that are problems for them: transportation and negative labeling or stereotyping. Para-transit services are not always reliable, don’t go where they need to go, or have limited hours. The second concern regarding labeling was a very sensitive subject. One man said that he wished that it was against the law to use the “R” word (retarded) and that “people first” language should be used.

Families with children/adults living at Residential Habilitation Centers:

- ❖ The universal answer to the question of what is working was, “Everything!” For the families whose son or daughter has lived in the RHC five years or less, many seemed extremely traumatized by the events that occurred before their situation was deemed emergent enough for admission. In the words of one parent, “The system failed him.” For these parents, an environment with enough well-trained staff to

respond to a critical incident when needed, doctors experienced with managing complicated medications and behaviors, and an environment perceived as safe, accepting, and loving with little staff turnover was “a dream come true.” For RHC parents, what was not working were budget cuts that impacted recreational programs, such as the pool at Fircrest and staff cuts that impacted community outings. In the group for families of residents who had lived there more than 20 years, one parent felt that all would be well if DDD would quit running the facility like it’s going to be closed.

QUESTION 4: WHAT DOES IT TAKE FOR YOU TO TRUST THAT COMMUNITY PROGRAMS CAN SUPPORT YOUR CHILD?

Families with children/adults living at home:

- ❖ For the families of the toddlers and school age children in the community, it is hard to look into the future as they are trying to simply make it through the day. Values such as, “people who really care,” and “well trained staff,” and monitoring on the part of state government were important. As one mother put it, “I would need personal knowledge that I can trust community programs.” For the families of teens and young adults, first-hand knowledge of any program also was important to their ability to trust, with parental involvement and research the key. For the families who have children in supported living programs, better staff salaries and more training was identified as important to being able to trusting community programs. Some family members wanted to know that there would be back-up if something went wrong, if there was a “meltdown.” One mother summed it up when she said, “The community has to earn my trust.”
- ❖ Family members with children who are nonverbal were particularly concerned about trusting the community for fear of abuse or poor care that could not be self-reported by their family member.
- ❖ Thinking about out-of-home placement led to one group participant to express the fear of “what will happen when I die?”

Self-advocates with developmental disabilities living in the community:

- ❖ As one person put it, “I have a hard time trusting people.” Another person answered, “It takes a lot. Trust is a very strong word.” For a third person, who felt that he had been lied to, “trust goes both ways.”
- ❖ Several people mentioned that they have been lied to and had things stolen or knew people who had things stolen by staff. Another person mentioned that she didn’t like it when the staff cancel appointments to meet with the participants.

Families with children/adults living at Residential Habilitation Centers:

- ❖ The attributes that are most important to the RHC families were that their family member be in a safe place, with well paid and well trained staff, including medical

personnel who are minutes away, space to move around without the dangers of being in a city, and the ability to bring in extra staff at a moment's notice in the event of a crisis, particularly behavioral intervention. Because many of them had negative experiences with community services, they could not believe that anything other than an institution with concentrated services could serve their child successfully. As one focus group participant put it, "I've lost my trust! There is nothing they can do to regain my trust."

- ❖ For some parents, there does not seem to be enough quality assurance and monitoring in the community. For two families with children in the nursing facilities within the RHCs, there was the belief that the quality of nursing care was so much better than the community, particularly with staff turnover in community facilities a well-known problem.
- ❖ One family member summed it up with the statement that, "They would have to prove that they could keep him, happy, healthy and safe."

QUESTION 5: HOW COULD INSTITUTION WORKERS HELP PEOPLE IN THE COMMUNITY?

- ❖ The families of toddlers and elementary school age children in the community had no idea how to answer this question. As a father of a teenager said, "The question is odd to us because most of us have spent a lot of time trying to avoid the institution."
- ❖ Community family members thought the RHCs might offer respite, medication management, and therapies, and that instead of going to the hospital, people with developmental disabilities could receive treatment from the institution. Others thought that RHC staff could use their expertise to assist community programs.
- ❖ For self-advocates, particularly those who lived at an RHC in the past, they did not even want to address this question. One person remarked that, "the institutions just warehouse people and that is wrong."
- ❖ RHC families, on the other hand, would like to see the RHCs either expanded to serve more clients on campus and/or offer their services, such as medical, dental, physical therapy, and speech therapy, on an outpatient basis. As one family member at Lakeland Village put it, "I would like to see more education in the community about what Lakeland Village really is; it's not a place for warehousing."

QUESTION 6: LOOKING INTO THE FUTURE, IF YOU COULD HAVE THREE WISHES FOR YOUR SON/DAUGHTER/RELATIVE, WHAT WOULD THEY BE?

- ❖ Families in the community want their children to be happy, healthy, and safe; to have jobs, meaningful activities, and friendships with peers and people in their lives who will care for and about them; to have opportunities to be a contributing member of

society; and to be valued for who they are. In terms of day-to-day living, families want access to waiver services, access to speech and other means of communication, good medical care, for adults a supported living type of situation with compatible roommates, and in general, the ability to live a quality life.

- ❖ Self-advocates talked about better public transportation, particularly for people who depend on para-transit services. They want to “live the same lives as anyone else” and not face discrimination and be treated as though they are less valuable than others. Some want better jobs and worry about budget cuts and the impacts that will have on their residential programs.
- ❖ RHC families also want their family members to be healthy, happy, and safe, although they expressed their wishes more in the context of their family member continuing to live in a state operated institution. Their wishes tended to be very practical, for example “Keep Lakeland open,” or reopen the pool at Fircrest School. One parent wished for “peace of mind that he will be well cared for when we are gone and not be in the middle of these political turf battles over resources.”

QUESTION 7: IS THERE ANYTHING ELSE YOU WOULD LIKE TO ADD TO OUR DISCUSSION TODAY?

- ❖ The young parents were concerned about what happens after age three and having too much income to qualify for services. The parents with school age children talked about needing more help at home and help with understanding the system of services. In the older students group, the parents are worried about future funding for jobs, residential programs, and mental health services. Several people from different groups expressed concern over future health care changes and how that will impact their son or daughter. The theme of navigating through a confusing system of services was again noted by the families of adults who are contemplating out-of-home placements.
- ❖ Seattle self-advocates were pleased that, “the issues are being recognized” and reiterated that transportation is a problem. The Tacoma self-advocates are aware of what it means to make budget cuts and hope that DDD will not cut programs.
- ❖ RHC families want “lawmakers and policy makers to know what crisis truly looks like.” They want people “in the hierarchy” to get out and see what RHCs are all about. For others, they wanted to know if this report would make a difference or if the next study included in the Supplemental Budget would include this information, too. For one father, it was all about working together: “I see other uses at this campus and it would be more efficient if we could all work together. So many groups are trying to get the same dollar. It’s not benefiting either one—there must be a better way to work together.”

DISCUSSION

The focus group participants expressed a variety of points of view, depending on the needs of their family member and the course of their experiences. Families tended to desire the same things when thinking about the future, although the question of how to get there was often different.

For community families and self-advocates, several themes stood out:

1. Navigating the system and becoming knowledgeable about practical issues, such as guardianship, is a challenge. Families of school age children feel dependent on their school district for information and “don’t know what they don’t know.” Even though there are materials available from DDD as well as various advocacy groups, the information is not reaching the average person/family.
2. Medicaid Personal Care and respite are critical for many families, especially single parents and families without relatives nearby. Are there ways to help certain families with more hours where the need is extremely critical? Is there a way to provide safe, quality out-of-home respite for families that need a vacation or time away that will help them manage for the rest of the year?
3. More training for families and teachers about autism is needed - what are best practices, how do parents manage with children who need routines that are not easy for a family to follow? How can the community be more educated about children with autism and the problems that families face raising a child with unique social and learning needs?
4. There are still barriers and problems with using public transportation for people with disabilities - it needs to be easier for them to be a part of their communities.
5. The issues of high turnover of staff in community programs and better staff training are concerns to families and consumers with disabilities who want to be able to trust in community programs. Community families also are concerned about safety and believe that a strong family presence is important for ensuring their family member receives good care.
6. Families need help addressing the “what happens after I’m gone” question.

Themes from the RHC focus groups included recognizing that:

1. A safe environment and well trained staff with little turnover are critical factors for families who are happy with their family member living in an institution.
2. Some people with developmental disabilities need more staffing and medical/behavioral support than the typical community program can provide with current resources, and the RHCs can meet those needs.

3. The institutions are a home to the people who live there and shouldn't be thought of as something less.
4. Some families do want their children to move back to the community and are frustrated by the lack of community resources and options to meet their child's needs.
5. For families with a history of failure in community settings, who have finally found success and stability for their son or daughter, "if it ain't broke, don't fix it."

As DDD faces the future, what are the pressures and challenges?

- The prevalence of autism spectrum disorders is rapidly increasing and is now estimated at 1:110 children, up from 1:166 ten years ago.
- Medical advancements ensure that more medically fragile children survive and need support.
- Individuals with Disabilities Education Act (IDEA), Head Start, ChildFind, and other early intervention programs have identified children in need of service, increasing demand.
- Public policy ensures a substantial investment in a "free and appropriate public education" for students with disabilities. At age 21, that investment stops which has a significant impact on the graduating student and his/ her family.
- The prevalence of public school graduates has not increased in recent years, but early identification and personal expectations have increased the demand for public services.

CONCLUSION

The Division of Developmental Disabilities currently provides supports to approximately 24,000 people living in the community and 915 clients living in RHCs (December 2009). There are approximately 38,000 Washington residents with a qualifying disability, which means that the current system of supports reaches only 63% of eligible clients. Clearly, the system of care for people with developmental disabilities relies on and shares responsibility with many individuals and families. Caregivers are providing support for longer periods of their lives and the caregivers are aging. Anything that may be done to support families in a positive way to in turn support their family members in the community will be beneficial for all.

What can DDD do?

1. Improve training and technical assistance efforts so that people with disabilities and their families build trust in their community service system.
2. Continue to build a system of supports for people with developmental disabilities that will meet more of the significant and growing unmet needs of families and consumers, including:
 - a. Strengthening respite, both in-home and out-of home, and Medicaid Personal Care services;
 - b. Providing behavioral and medication management supports; and
 - c. Working with school districts to educate families about services and answer their basic questions.
3. Develop a cost effective, efficient strategy to make information more readily accessible to families and advocates.
4. Take the lead on initiating a joint effort with the Office of Superintendent of Public Instruction (OSPI) to identify best practices and options for working with individuals with autism spectrum disorders.
5. Continue to support consumers with developmental disabilities to live in, contribute to, and participate in their communities as much as possible, including employment.
6. Influence, whenever possible, transportation options for individuals with disabilities.
7. Examine the options for sharing the resources and expertise of the RHCs with community families and clients.
8. Address the issue of staff turnover that is of concern to families and clients alike.
9. Make the necessary investments in community supports that Governor Gregoire outlined in her 2010 policy brief, *Reforming How We Care for Washingtonians with Developmental Disabilities*.

APPENDIX

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Methodology

A total of twelve focus groups were held, including six groups organized by staff from each DSHS/DDD region, three at the residential habilitation centers (Fircrest School, Rainier School and Lakeland Village), and two groups of self-advocates with developmental disabilities, and one initial practice group. The focus groups were formed with the following demographics in mind:

- Group 1: Families of children birth to three living at home (Region 3)
- Group 2: Families of children ages 4 – 11 living at home (Region 2)
- Group 3: Family of people ages 12 – 17 living at home (Region 5)
- Group 4: Families of people ages 18 – 30 living at home (Region 4)
- Group 5: Families of teenagers & young adults (Initial group)
- Group 6: Families of people ages 31 living at home (Region 6)
- Group 7: Families of people who have always lived at home (Region 1)
- Group 8: Self-advocates living in community (Region 4)
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- Group 10: Families of children admitted to RHC within the last 5 years (Fircrest)
- Group 11: Families of adults admitted to RHC within the last 5 years (Rainier)
- Group 12: Families of long term (over 20 years) residents (Lakeland Village)

Staff were asked to consider other demographics when inviting participants, such as rural versus urban, age and gender, level of support needed by the person with the disability, intensive medical or behavioral issues, employment or day program, and community residential setting if not living at home.

A practice group was conducted before meeting with the groups to test the questions and format. This group did not recommend any changes to the process; therefore, the comments of the participants were included in the report. The focus group discussions lasted approximately two hours and were typically held in a conference room at a regional office or the RHC where distractions could be kept to a minimum. All focus groups had the same facilitator, questions, and agenda. Four groups had the same note taker, with the other eight groups having different note takers. Note takers attempted to capture the notes verbatim; however, the note takers were volunteers, not professional transcriptionists. Some note takers wrote their notes in the order they were stated; a few others recorded the notes by order of their participant number, not the order of the discussion.

The facilitator also took notes on poster paper which served three functions: it slowed the pace of conversation down for the note taker to keep up, allowed the participants to see what was being written and provided continuity between the twelve groups. The facilitator was able to compare the note takers' notes to the poster notes to capture as much of the dialogue as possible.

In order to protect confidentiality, focus groups participants were assigned a number, Participant 1, Participant 2, etc. All comments were identified by this number and names were not included in the notes. Recording the participant number with that person's comment was useful in the analysis to determine if a theme or issue was repeated several times by the same person or was noted by others, as well.

GROUP 1: FAMILIES OF CHILDREN BIRTH TO 3 LIVING AT HOME (REGION 3 FOCUS GROUP NOTES)

April 20, 2010

Focus Group Questions:

Question 1: What services does your family member currently receive?

- P1:** MPC hours, Medical Coupon, DDD preschool and therapies.
- P2:** Son (3½) - Multiple Medical needs. In-home care, Toddler Learning Center, speech and physical Therapies. Infant/parent educator, continually working on cognitive skills, Family Resource Coordinator.
- P3:** Speech and Physical Therapies, medical coupon, Social Security, Family Resource Coordinator.

Question 2: What is working well for your family member?

- P1:** That I have them. Having MPC hours/ provider, makes it much easier and helps with outings; enables to include son in the community.
- P2:** In-home therapies. Works well with our schedules.
- P3:** Therapy. Medical coupon. Social Security income provides extras that other services don't pay for.

Question 3: Is there anything you wish was different or could be changed?

- P1:** Preschool won't have non-disability kids because they don't qualify. Frustrated that waiver services are not income based. Waiting list is too long. Need more consideration on what individual supports are needed. For example, medical debt, physical toll on the family as the child grows larger and ages. Therapy piece will be cut off when child is 6 or 7. If they can't get all of the therapy they need now, it will be a lost cause. Have a long range goal of transitioning to live in the community. Also don't want to burden the big sister to care for my child when he/she is an adult. Am concerned about losing hope. We have had coupons in the past, so we haven't experienced capping out on insurance yet.
- P2:** Transitioning stage – Our parent support person's hours were cut. Now it is hard to connect with other parents. They need to move dollars around to keep these hours in place. I have a pamphlet on inclusion. Toddler learning center was also cut. Need these services to be able to connect. Spoon fed information is not always the best. Need a table or coordination of sources. Transitioning services needed and options when my child goes to school. Medical bills have decreased as we have evolved. Worried about capping out in the education system. Life skill training time. Don't want the system to hold her back (i.e., holding her back a year). Should we keep her in preschool an extra year? Handing off care, what might she encounter. Parent booklet – these are things I like, these are things I don't like. I share the same issues with costly medical. We are looking at Head Start, which has therapies. Have to figure out what works for our family.
- P3:** Happy with current services. I am concerned that when she will be in the school district, that she will be separated from other children because she has a disability. Don't want

her to be treated differently. Diagnosis of delayed, I don't think they should be pushed away from others because she is delayed. Most of family knows signing.

Question 4: What does it take for you to trust that community programs can support your child?

- P1:** Educate the community what is appropriate language and terminology – Understanding grief cycle, so they know how parents think. Competitive pay to sustain employees so there is less turn over. Would prefer to go through an agency. People in general, outdated terms. Social networking through jobs – good doorway. Need more money allocated to fund jobs for people with disabilities.
- P2:** TLC – the right thing to say would depend on the day. Need good communication, knows what's going on. What the goals for the day or month are? Know what the program is working toward. Would like to observe the program before I place my child. Issue-want to bus her to school. Want my child to be more verbal and be able to speak up if someone is a "bad" person. Concerned about child being non-verbal and not being able to report abuse, or know what abuse is. Parent involvement is critical.
- P3:** Want her to be treated differently because of a disability. Need personal knowledge that I can trust community programs. So far, okay.

Question 5: How could institution workers help people in the community?

- P1:** Good intentions, but workers seem to be more worried about losing their jobs rather than caring for a family member. Families want community services and are willing to relocate. Workers can remove themselves from the thought of being let go, need to think about relocate and move into the community, but continue to work with people in the community.
- P2:** Nothing to add.
- P3:** No opinion.

Question 6: Looking into the future, if you could have three wishes for your son/daughter/relative, what would they be?

- P1:** Be happy, and be a contributing member of society. Would like to be placed on the waiver, primarily so he can be supported at home until the age of 21. Would like to receive employment services, and transition into living in the community at age 21.
- P2:** Be happy, be a contributing member of society, and be respected for whom she is, and is a valued person.
- PA:** Allow the same opportunity as anyone else. Don't let her disability get in her way of success, or be judged by who she is. I hope she will be able to talk and be understood.

Question 7: Is there anything else you would like to add to our discussion today?

- P1:** Parent to parent program did not get cut, or was saved. Waiver – find a way to look at more significant cases level of care, and get them on the waiver. If my spouse and I were divorced, my child would qualify for more services. Need to free up funds for people with most significant disabilities, regardless of income. Should review people

currently on the waiver who may not need those services. Move the money around as other waiver clients need.

P2: I love the Birth to Three program. I have concerns when we get past age three. Family Resource Coordinator wanted from age 4 to 7; help me direct myself through the process of what's next. Need a navigator.

P3: DSHS Community Services Division should be more diligent in figuring out who is qualified for services and who is lying. DDD needs more money for services.

GROUP 2: FAMILIES OF CHILDREN 4 TO 11 LIVING AT HOME (REGION 2 FOCUS GROUP NOTES)

April 23, 2010

Focus Group Questions:

Question 1: What services does your family member currently receive?

- P3:** Services from school; outpatient at hospital OT/PT.
- P9:** School services.
- P8:** School, outpatient at hospital for OT/PT, mental health counselor, Medicaid Personal Care (MPC), autism room, life skills.
- P7:** MPC, speech and physical therapies, OT.
- P10:** MPC, occupational, physical, and speech therapies.
- P5:** MPC and special education.
- P2:** MPC, school, used to have OT and speech.
- P1:** MPC.

Question 2: What is working well for your family member?

- P1:** MPC worker is a big help.
- P2:** Helper does not receive mileage or gas; child fears bus driver; helper helps with morning care – dressing; would like more hours.
- P4:** MPC works.
- P7:** MPC works well (grandmother).
- P8:** Children have different diagnosis; helper takes one, parent takes one, especially in the evening.
- P9:** The school is awesome. They have well trained staff: 5 staff for 10 children.
- P3:** The teacher he has now is the best ever for my son.
- P10:** Therapy services are terrific; very pleased; changes made when needed; DDD helped with therapeutic apparatus in the home.

Question 3: Is there anything you wish was different or could be changed?

- P10:** (Re DDD) Wishes care providers were more thoroughly trained in working with children with disabilities; not sure contracted services are training providers sufficiently; care providers not ready to provide care when they arrive – have to be trained by parents; children like consistency of regular members – like family; proposed basic instructions for child w/autism; provider needs to know what they can tolerate; not everyone can

handle everything; how to work with medical apparatus; comfortable working with child w/autism; their expectations are different than what the job requires. Agencies send whomever they want; parent wants "non smoker" and consistency; parent does not want strangers taking care of child – she wants one person; parent wants child to not trust strangers; take advocate with you to request help; parent can have skills desired written on IEP; if there is a substitute teacher, parent may opt to keep child at home that day – same with different bus driver – parents need to make those decisions.

- P8:** Goes through DD office as working with provider agency doesn't work; caregiver not able to work with child; caregiver watches TV because they do not know what to do; frustrated that services do not understand parent wants to move forward with training children – no pay to train children; overwhelming – non-stop daily; child care not available for special needs children; parent sends notebook w/child to school for teacher to write in how child's day was; not much communication from teachers. Provider turnover is very frustrating, the kids get upset.
- P2:** Agencies need to train their staff better; babysitter needs to hold child before putting on bus; providers need to be trained for child; parents train caregiver; wants caregiver to have more patience with child; child knows routine and does better with one provider they can trust; had to find day care close to work – cost was \$1200 month; no special needs in day care; took classes for care at night so she could take care of child; needs more information for IEP; how many hours does child need for OT/PT in school – wants to know more about what does on in classroom. Parent wants more orientation to help with own child; many people involved with child; needs good doctor; parent wants extra therapy after school. Child does not like regular bus driver – does not want to ride bus; parent went to principal and school office to discuss this issue; parent wants list of providers that can really help.
- P10:** Agencies want to send whoever is available, so the parent has to say what they want. We need consistency. It's difficult to teach when to trust a stranger.
- P3:** Child is autistic and high functioning; babysitter came in morning; day care centers do not do part-time; mother stays home to ready one child; there are no home services for high functioning children; no books available to help raise children; parent has no paid hours; better for children in home environment; appointments difficult to make; work all week without help with chores; school does not follow IEP well; at 10 years old, parent has seen more progress; parent needs to train the school; parent wants child to learn skills and independence; child cannot rely on parents for rest of life; babysitter no longer available.
- P2:** I was charged extra for day care for my disabled child but didn't receive anything special for it.
- P9:** Would like to set up house like the school does; needs someone to show her what will work; child in school most of the day; parent not able to work; they make too much money for services; want to invest money in child now for improvements as child grows.
- P3:** I have the same problem. When my son is old enough to move away from home, I will make sure he has his own place. I want to be a mom, not the caregiver.
- P8:** I'm a single mom, can't work, and need state assistance. My situation is not going to change and it's very hard as I have to be there the kids (two children with disabilities). It's very difficult; it needs to be easier, it's overwhelming.

- P7:** I'm a single parent, financially unable to leave my parents' home; cannot change caregivers from the grandparents; would love the idea of caregivers having training in our home. My child needs help now while brain is developing; seizures before prevented learning; does not need ABCs or numbers at this time; instead he needs to learn to dress himself – life skills – basic necessities. She would like people trained to teach her child and help her. The situation puts a strain on the grandparents and it's confusing as to who is in charge - me or my parents.
- P5:** Need more respite hours. Teachers need more training on autism. Providers need more training, too.
- P2:** I need more information, especially on how to deal with the IEP.
- P6:** People who do not have this problem, do not understand the problem.
- P4:** Would like to see more respite available; teachers need more training working with children of autism; parent needs training on how to work w/child; wants providers to be better trained; need for child care when 12 years old and up – in limbo.
- P1:** Has same issues; teenagers are difficult; would love to call someone to ask what they did with similar problems – a support group; one child hated grade school, but loved middle school, hates high school; other child loved school; homeschooling helps – use patience, kindness. "Homelink" is 2 days per week. Children behind regular schooling; grateful for hours available from case worker; wants older caregiver; parent never leaves child with caregiver; children know if person has authority; needs help with chores – does 4-5 loads of laundry per day; morning to night spinning wheels trying to keep house clean.
- P5:** Part of the problem is that you can't use respite for the parent to be able to work.
- P10:** Would like to see it mandated that parents need to be informed when there are substitute teachers or a different bus driver. Some children won't deal with change, any change, so we need to know.
- P2:** My son is very upset with his bus driver.

Question 4: What does it take for you to trust that community programs can support your child?

- P4:** As my child progresses, I will trust more. Will try schools more; want to see more activities for children; a community center for culture and sports, for example.
- P8:** Hard to look into future; concerned about "today;" hard to put trust in people; parent will grow with child; teachers do try, but need to educate other children in classroom – everyone needs to be educated; others need tolerance.
- P9:** I want my son to move when he grows up. A group home might work. My child is happy to do things on own; I've considered a group home but concerned about screening staff. It's scary.
- P3:** Parent not sure if she can trust; she will find right person; parent would like to see teachers go through special needs class.

P10: Teachers need more training to work with special education children; wants to see properly trained aides in classroom; child-to-adult ratio needs improvement; wants to see far better training in community setting; less expectations in child's abilities, behaviors; people need to try and understand children – not assume. ARC needs better trained aides for their summer programs – not teens without experience. Parent will not allow child to go to pool or theatre with teen. Transportation is an issue; community programs do not have housing for DD; support or monitoring is a huge issue.

P1: I look for people who really care. I want to always be there. I know their unexpected behaviors. Don't allow children to go with stranger because they can get hurt so easily; children considered mildly retarded; facilities must be monitored; would not allow children to partake in community at this time; some workers are good with children.

P2: Our children are easily abused by other children and adults; safety is a big issue.

Question 5: How could institution workers help people in the community?

P10: Variation among DD children – some do better at home; in group home; need more support; where do children go when parents unable to parent or choose not to any longer? What are the state's plans for supportive housing services for DD adult? Legal system needs to understand that DD individuals need to stay out of the jails.

Question 6: Looking into the future, if you could have three wishes for your son/daughter/relative, what would they be?

P3: Be independent; have a profession – work; to be safe.

P9: Needs way to communicate – child nonverbal.

P8: Healthy, happy and safe; be self-sufficient; have jobs.

P5: More independent – communication; have opportunities to do sports; mother wants more education to work with child.

P2: Receive therapies child needs to grow in future; independent; best education; have a normal life.

P1: Security; place to live; employment; someone who looks after them who cares.

P10: Mature enough to be a self-advocate; desires child to be protected in a supervised and loving environment; helpers who truly have only her best interests in life without taking advantage of her; to be safe.

Question 7: Wrap-up: Is there anything else you would like to add to our discussion today?

P1: Needs chore person to help so parent can work with children; fears for children, but wants children's interests to be encouraged/promoted; worried and want to know if children will receive less health care (when national program is implemented).

P3: Needs chore person to help based on child's ability; need more help as a single mother.

- P8:** Before decisions are made to cut or add programs, decision makers need to meet with parents to see what they need first; changes needed; what happens when funding runs out.
- P10:** Cannot get daycare; respite hours so few; beneficial for parents to have a local drop off day care/respite/retreat area for mental health purposes; if parents in hospital, who would care for child? Parents need information regarding respite at RHCs/other facilities; need out-of-home respite to look forward to a break, sometimes you need a vacation from your child. Parent wants state to do more ads or send information nationally to encourage understanding and tolerance for DD children; general public need to understand child's peculiarities and not give unsolicited advice.
- P4:** Ask secretary (DSHS) to read report.
- P2:** How will health care affect DD children? Child in diapers is expensive; wants extra money to help with child's supplies. Medicare does not cover wipes; needs gloves. Doctor appointments not often enough; will insurance supply for special children? What will DD programs offer? Parent needs counselors; each family has different needs; respite and proper information; guardianship; parents need help to know what is really available for medical, physical, etc.

GROUP 3: FAMILIES OF CHILDREN 12 TO 17 LIVING AT HOME (REGION 5 FOCUS GROUP NOTES)

April 19, 2010

Focus Group Questions:

Question 1: What services does your family member currently receive?

- P1:** Respite care, care provider after school.
- P4:** MPC hours, 20 respite hours per month, Basic Plus waiver, trouble finding Nurse Delegation provider.
- P8:** Have a great case manager. Respite during summer and sending him to camps.
- P10:** Functional skills class at high school. One of the 2 children has an MPC provider. Waiting for respite.
- P11:** See P10.

Question 2: What is working well for your family member?

- P1:** The fact that we do have a nominal amount of money to dedicate to various things, such as camp, after school support from care provider. The schools have had terrific teachers. Good in inclusion programs. Has worked in many places, has some vocational training.
- P4:** Situation is unique, is a single mother, no family in the area. Without the MPC hours I wouldn't be able to have her home. Like that my oldest daughter is able to be contracted at this time. Do like that I feel I can talk to my case manager and get the help I need. Seems like you care about my daughter.
- P8:** With the help of the YMCA, doctors, school district. Was expected to be in an institution, etc. Through all the services with after school care and camps, my son has made a miraculous recovery, straight A student, can't tell he has autism unless a medical professional. Taught to swim and roller skate. Reading physics books.
- P10:** The school district since junior high, the teachers were in tune with special needs and now in high school, the teacher has lots of good experience. One of them is learning life skills. Went to Mary Bridge to learn how to walk. Sings in the choir. She can hear a song one time and remembers every word. The youngest one has severe autism. Have tried to communicate with her. She has her own sign language. The school is doing a lot for her. They were UW case studies at the time.

Question 3: Is there anything you wish was different or could be changed?

- P1:** She was on the homecoming court as a senior at school. In some of the mainstream classes needed better inclusion such as swimming and PE. Would like to see DDD get more active in creating a road map for someone like myself that aren't heavily vested in these programs. It would be nice to see what programs we qualify for. Don't know where to start. Age and need specific. A web based solution where a person can type in special needs and understand what they are up against in that area. (Staff will get him the Road Map to Services brochure and WAC references.) You don't know what

you don't know. Would like to see not-for-profit and for-profit networking. I created an easy critical information card for families. It puts all the information in to help people understand about the person. This information would assist in networking at camps, paramedics, teachers, etc. Has prescription information on it.

- P4:** The MPC hours, allow providers under the age of 18. Many other states do. Must come home from work, and must work all night doing the care. If I could find people to be care providers. It would be easier if I could just stay home and take care of her. Assisting with additional funding and increase in provider pay for the care givers. Need more pay, more hours. Don't get much help from school. Would like to have one hour every day. Any more would be hard for medically fragile. Teachers that are better trained in physical disabilities. Until 18, not allowed supervision hours. Can't get any for a 16 year old child. She cannot do anything for herself. I feel like I am sinking. It takes 2 months to get contracted and person may have found another job in those 2 months. Want my daughter to get the best care possible.
- P8:** If there's any way to work with the school district to train them on autism. Math teacher is constantly correcting him and asks him to look her in the eyes. When he came out of special education, he had to transfer to his home school. During the transfer, it was scary for her. One of the teachers was smart enough to take a kid and have him mainstream and help him. Shadowing him was very helpful. Being with that child made the major difference. Try to find non-competition social activities. If there could be legal help when the parents split up to be sure the child's best interest is taken care of. Sometimes one parent must do all the appointments and it is difficult to hold a job.
- P10:** What is out there for her when they turn 21? Older daughter will take over care when we cannot care for them. What is out there to help us with their care? Also, the state requires that the person have an ID card at a certain age. The state should give us one or supply them for the individual. Debbie said to ask case manager about help getting this.

Question 4: What does it take for you to trust that community programs can support your child?

- P1:** What are the community programs? Would have to be intimate with the facility. The GAP program owns 4 homes, are adult family living. Are landlords of the property for 3 and run one. All the rules with how the money can be used should be made so there could be no error. Parental involvement and research. Never an institution will ever happen. It would have to be a very small group for my child to live elsewhere. The drawback with a facility is that there would be stereotyping and all kids can't be taught the same way, treated the same way. My child having her own apartment wouldn't be good as she is too social.
- P4:** Don't think there is anything a person can do to make me trust another living situation for my child. I will take care of my child forever. Hope my family would help to keep them out of any other home. Budget cuts are frightening.
- P8:** Have asked relatives to keep an eye on them if anything happens to me. Expect to be figuring out how to get enough money to get him into college and will there be support from the Governor. Want him to get his education.
- P10:** Suggested P8 ask the Gates Foundation for a scholarship.

P10: Have discussed their future abilities. Our children with autism wouldn't be good institution candidates. Our problem is that our youngest couldn't adjust to a different residential setting. It took a long time for them to interact with the caregivers. Finding someone who understands our child is major. Our family members wouldn't allow us to place them elsewhere.

Question 5: How could institution workers help people in the community?

P1: No.

P10: If it were like Mary Bridge, they would be specialized in special needs and life challenges.

Question 6: Looking into the future, if you could have three wishes for your son/daughter/relative, what would they be?

P1: A sense of self purpose. Happiness. Ensuring there's a place for her in the job world. A safe environment.

P4: To feel loved, cared for. Have the best life I am able to give her. Would like for her to be able to get out of her wheelchair. Miss her being able to run and play like a child.

P8: Wish he would quit calling me a hovering helicopter mom. Hope they don't put me in a home some day. Hope someone sees what is in him and helps him do something with his gift. Wish he would do something fantastic in autism. Wish we could change the immunization program within the U.S.; don't do 3 shots together, ban mercury from them, space them all out within a year, use the test to see if a child could experience side effects from the shots. Want to see something come of the class action lawsuits.

P10: For the oldest child, having a fulfilling and happy life and doing what she wants to do.

P11: For the youngest, I would want speech. Fulfillment for her life and being happy in her life.

Question 7: Wrap-up: Is there anything else you would like to add to our discussion today?

P1: The most costly programs are institutions. If the state doesn't want to fund them in the future, what are they doing to do instead? At some point you have to build the alternative or you need to incentivize the alternatives to care for them. There is a huge need in certain areas, yet not funded by the government. Too much division. The funding for the programs such as the work programs is important. I am worried the funding is changing and there won't be programs available that my child has had the benefit of.

P8: What are you going to do to show the Governor the success stories of children staying at home?

P10: When both kids were reviewed, they came out with a new system of reviews. Were doing it on an annual basis and now are changing. If something happens you can do a significant change. The staff said there isn't going to be a change in them yet. The state was paying \$17.50 to residential care for providers, and family providers should get more rather than less as they currently get. We hear that they want to break up DSHS.

If you broke off, would DDD be a stand alone? Thurston County does stuff for the kids but we have to go to Tacoma to get services. Most of the money for special needs kids comes from the Federal Government. We found children in special needs classes that weren't special needs but they had to have a quota or lose the program. They had a sexually deviant kid in one of their programs along with other trouble makers. It became a dumping ground for troublesome kids.

**GROUP 4: FAMILIES OF CHILDREN 18 TI 30 LIVING AT HOME
(REGION 4 FOCUS GROUP NOTES)**

April 22, 2010

Focus Group Questions:

Question 1: What services does your family member currently receive?

- P1:** My daughter receives SSDI, Medicaid and respite services and a job coach for her job and transportation from Access.
- P4:** My daughter receives SSI and Medicaid and respite services and an employment specialist is trying to find her a job.
- P6:** My child receives SSI, Medicaid and respite services.
- P7:** My child receives SSI, Medicaid, and respite.
- P8:** SSI, Medicaid, SSI, job coach.
- P11:** SSI, Medicaid, respite.
- P9:** SSI, Medicaid, respite.
- P2:** SSI, Medicaid, Medicaid Personal Care, Family Support money, Division of Vocational Rehabilitation. (DVR).

Question 2: What is working well for your family member?

- P11:** I have no complaints, but it could be better.
- P8:** Having SSI is helpful and we just started receiving respite services in August and that has been a lifesaver. The respite has saved our family.
- P9:** SSI, we have not used respite recently, but it has been great in the past. She gets Medicaid Personal Care and it is helpful to have the reimbursement for mileage.
- P7:** SSI, Respite.
- P6:** My DDD Case Manager is very helpful. She recently gave me the information I needed for my dentist to accept my son as a patient. Our job coach at Trillium is very good even though she only provides 6 hours of service and there is good communication. We have a good DVR counselor and a mentor. His son was ahead of my son by 4 or 5 years and he mentored me. Then I mentored other parents. His role as a mentor on practical matters was very helpful to me and others.
- P4:** We go to Elder day services in Des Moines during the day so I can go to work and that helps me a lot. SSI is great and the parks programs are great. She also has track at Shoreline and that's great for her.
- P2:** All services are working well except one.

P1: All services are working well - especially the DDD case manager and the job coach are really great. We just started respite care so we have not tried it out yet and don't know. SSDI is good to get but it is complicated to compute hours.

P6: SIDE QUESTION: How will the new health care bill affect my son's Medicaid services?

Question 3: Is there anything you wish was different or could be changed?

P4: We just lost our respite provider and our job coach can't find her a job.

P2: The flow of information and how a parent takes a child from pre-school (or birth, really) through the adult service system is complicated. We had to start filling out forms early on for therapy services, then there is the whole IEP stuff, and psychologist meeting. How are we supposed to best advocate for our kids? Do we do it the way the school wants or we want? What do we do first to get our kid ready when they are in high school? My son had significant health issues, so he could not use those years to get ready for job situations. Now, the part that is not working well is DVR. At this point, he has very few services available, and I don't know who to go to make sure there is funding there for him to be successful.

P1: What is the order of everything? When do you do guardianship? At what age do you do what? How do you address housing? What is the flow chart?

P4: How do I find respite care providers? I need a list of respite care providers. It would be really neat if the respite care providers didn't have to come to our house; sometimes I want to stay home with my husband. I heard they can only have one child at a time. We need to find an adult day care where several people can go so parents can go to work. I called all the respite care providers from my case manager but they were really nursing home providers. She didn't really have a list of respite care providers.

P6: The things that are not working well are the need to do advance planning for our son, but we've been told that we can't activate the system until we are ready to do it now. Having a list of 150 group homes is not helpful, and we need time to process the information and get comfortable with it. Right now we can't get comfortable with the idea of it, and the system seems to be only set up for emergencies.

P7: My daughter will be 21 in November, and I work right now, and I want to continue working, but what do I do with her when she is no longer in school? I am her volunteer job coach at her volunteer job. If I could get a job coach to help her on her volunteer job, that gives me a break and gets her used to having a job coach. The school district was not receptive to the idea at the first meeting. I met with the employment agency, but they were not receptive. My daughter is just starting to work next school year.

P8: When my son was in transition we went to DVR and they figured out he would be on Pathways to Employment. Then we picked a vendor and I am curious how many hours a month a vendor should provide. They can get paid for doing a job when they aren't doing much of a job at all. I don't want to burn a bridge, and I don't want to drop the vendor if it burns a bridge. I don't want to leave if I am not going to get anything better. How many hours a month should I expect from the job coach agency? I am not happy with my job coach services, but I don't want to drop them if I can't get anything better.

P9: There should be something that is accountable that says the job coach is working "x" amount of hours. My daughter was lucky to have natural supports at her employer, but it is because she had natural supports rather than paid job coach services. No one has

talked to us about my daughter's strengths. How can they expect to find her a job she likes and excels at if the job coach does not know her? It did NOT work for her to collect hangars for six weeks straight. It was frustrating to find her niche. It was very frustrating for her to sit home for 2 years after high school until she got her first job. There needs to be more justification for the hours.

P8: I take my son to work myself because I can't trust ACCESS bus services.

P2: We need to be ready for the future and we are not.

P1: Parents need better information about day care services and respite care services.

P11: My daughter needs 24 hour supervision. My wife and I have to juggle our schedules so someone is home with her all the time. I need help finding respite providers to call in an emergency.

P8: I was ready to move our son out of our home until we got respite care. We he finally got put on the waiver and got respite services; we are willing to keep him in the home. Our son gets bored with us and needs to be out in the community.

P9: I would like every case manager to talk to my daughter and not to me. Sometimes some of the case managers ask me the questions instead of my daughter. This seems to happen when the case manager comes from working with elders or seniors before they work at DDD.

Question 4: What does it take for you to trust that community programs can support your child?

P1: If the programs were stable and we knew the programs would be there into the future and not drop off in mid-stream.

P2: I agree with P1. What are the steps we need to take to be sure there will always be someone to watch out for my son or daughter?

P4: Getting to know the people who are teaching my daughter. I go every once in a while to her program to watch what is going on. I get involved before I send my daughter to anyplace new. Access is really scary – every three years you have to go into downtown Seattle to be sure she still needs hand to hand transport. Otherwise they just drop them off and who knows what would happen to her.

P6: I would like a letter from the DSHS to address all the issues that were spoken of in the Seattle Times. Then I might have some trust. There has been no letter from DSHS saying they recognize the issues and how they are going to address it. All there is right now is an article in the paper. Our trust factor just went DOWN because of the information in the article. We do not have a lot of confidence in adult housing or adult family homes.

P2: I am worried about my son's potential roommates. Is there someone who comes to talk to you about those arrangements?

P7: We feel good and we trust the recreational programs in our community. Looking down the road and we just re-did our wills. We have the guardianship, but it is hard to think of what will happen down the road after we are gone. We need information we can pass

on because you just never know. It is really an “on edge” feeling. We just need to be better informed.

- P8:** We are afraid to take a trip because what if something happens to us as parents? What will happen to our son or daughter? I got a list of AFHs one time and spent weeks doing “drive-bys.” Being able to thoroughly check out the program or a facility before my son or daughter moves there.
- P-9:** The program would have to have a proven record of quality care and have respect for my daughter as a person first. She is not a charity case, she is her own person. I would learn about good providers by talking with other parents.
- P11:** It would take a LOT for me to trust anyone. It is scary to leave her alone because she cannot talk and tell us the problem. I probably would not ever get trust. If there is a tightly controlled environment, then maybe. It took almost a year or a year and a half for my daughter to get along with others in a recreation program class, but she went with her school teacher and class and now I trust her being at that one program for 2 or 3 hours.

Question 5: How could institution workers help people in the community?

- P2:** I know one person who has a son in an RHC and his family would not want to be without it.
- P6:** They might be able to offer something to others, but I don’t know what it is, I’m not sure. These must be people with knowledge and experience, so what can they bring to the community? Could they come and tell us about the institution is the right thing to do? What it can and cannot offer. The question is odd to us because most of us have spent a lot of time trying to avoid the institution.
- P9:** Could the staff expertise be used in Adult Family Homes?
- P6:** Could they moonlight as respite care providers?
- P1:** Do they have rules that only certain people with certain licensing can work in an institution? They could offer student experiences to people who want to work in the field.

Question 6: Looking into the future, if you could have three wishes for your son/daughter/relative, what would they be?

- P1:** I hope my daughter can find a way to live on her own with support, and take the steps where she can be somewhat independent and happy. I want to be sure the healthcare is there for her.
- P2:** I had one wish come true. I would also like his independent living skills grow and for him to be happy and fulfilled in his life.
- P4:** To have a happy home when I do decide to put her in a home, to have enough money to do all her, and to have a good job. She loves to work, she needs a good job.

- P7:** Be in some type of supported living situation, be able to afford the little things she does now, and continue in her volunteer job. Do something that gives her meaning, and self-esteem. Wearing her uniform and name tag makes her feel proud.
- P8:** I hope I can find a safe, happy long term living situation for his long term future. He needs to have money available to have a social life with parks and recreation and activities and have self-esteem. He loves to work and he needs to feel like he is needed. He needs more job opportunities. I also wish he would get married to a really sweet girl and win the lottery. Good medical and dental benefits.
- P9:** She wants to have her own place, so a good supported living situation with a good roommate, and I want her to have a comparable lifestyle to what we have now with travel and family activities. I would like to see her be with a quality person in her life who likes to spend time with her.
- P11:** Everybody said what I want. My daughter loves to watch TV and listen to music. I would like her to have more social relationships and social activities. If we could find a safe and happy home I will think about that.
- P6:** I would like SSI to re-think what it takes to live. Another would be that my son would actually want to leave home.

Question 7: Wrap-up: Is there anything else you would like to add to our discussion today?

- P8:** My son goes on Wednesdays to a mental health program. There are many classes and support groups there. Lots of the students he went to school with are all up there – the ones that have not been lucky enough to get a job. It is a social thing and a learning thing for their kids. That program NEEDS to stay. There is a whole calendar of classes and it is very valuable. Job skills, social behavior skills, smoking or drinking. It does a lot of good for a lot of people. Also, another employment vendor has provided some real nice services for my son. Since he is completely non-verbal, they have provided us with telephone system and safety system. Also, the dental clinic – you end up at the Federal Way clinic, but if they don't take you, you have to go to another program.
- P2:** But that program would not call me back, our son could not get in to it. No place would accept coupons.
- P4:** We have had to fight for our daughter to be accepted by the same medical care providers as the rest of our family.
- P1:** Will we have to start all over again at a new doctor's if we move our son or daughter to a supported living facility?
- P6:** Be sure the DSHS Secretary addresses the issues in the Seattle Times. Reading those articles over two or three days drives the trust factor way down. It took the discussion about group homes off the agenda in our family's house. Even though it was not about family homes for people with developmental disabilities, we are afraid that it is not a big stretch to think it could happen to folks with developmental disabilities.
- P8:** I keep getting calls from my union, do you want to be transferred to another department. You have to keep your family members happy and healthy with enough hours with enough pay and enough respite to keep on going.

GROUP 5: FAMILIES OF TEENAGERS AND YOUNG ADULTS

(PRACTICE GROUP FOCUS GROUP NOTES)

March 11, 2010

Focus Group Questions:

Question 1: What services does your family member currently receive?

- P2:** How do you define services?
- P1:** Respite, Medicaid Personal Care (diapers), physical support, extended schooling until 21 (ESY), SSD.
- P2:** SSI, WAS Cap (food stamps), Medicaid coupon under DD, family member has MPC parent provider care, access to DECOD (Dental) at UW, and other services at UW.
- P3:** SSI, Medicaid coupon, Seattle Parks and Recreation services, Special Education, Swimming club, currently still in high school.
- P4:** Still in High School, ESY, CAP waiver, respite, family support money (under CAP), medical coupon as well, also receiving SSI.
- P5:** Medicaid personal care hours, DVR, School to work, with supported employment vendor funding from King County for supported employment, just approved for waiver, recreation services.
- P6:** None that I know of. (Participant has a child with dual diagnosis currently served by JRA.)
- P7:** Special education services, ESY services, DDD basic waiver, Medicaid medical coupons.

Question 2: What is working well for your family member?

- P1:** The whole package helps; most important is the respite (as a day to day feature), regardless of state's motivation. There has to be a focus on intensive support; there doesn't appear to be much in the way of an out of home respite feature. Anything that provides income is obviously helpful; in a single situation everything helps but you become very aware of what you need or don't have.
- P2:** Being a parent provider for MPC, without which my family member would be in an institution. In-home placement is the only alternative to state institution. Medicaid services outside of our county is working really well since there is not any in our own county - access to King County; need respite.
- P3:** Just started, but Medicaid is a financial lift on insurance. I'm surprised that someone will take care of my family member's medical bills (doctor accepts coupons), too soon to see any other benefits. Not happy with school but happy with what is happening or going to happen in the future hopefully.
- P2:** WASH Cap food benefits is a great thing, family member would have a really rough time without it.

- P4:** Transition Program gives family member opportunities. When you finish high school, 2 to 3 years in transition program on Shoreline CC campus they spend a shorter day 11-4 on a job site, then they go to the college and have life skill classes (cooking, other important experiences). A myriad of locations for jobs to see what kind of skills they have and where they need to develop more skills, see gaps. How do we fill these gaps? SSI is really nice, fortunate to have doctor take the Medicaid coupon - even though they suffer from taking it and are only getting so much money on the dollar.
- P1:** The solution for this would be to fund it, if DSHS funded OB- now I guess they do because it's now funded, it being a small population to provide a DD coupon - family member has it and uses it but only rarely; if you need this it needs to have this available. Small population so have it available with a higher cap. There should be a higher level of reimbursement for people with developmental disabilities.
- P5:** The Transition Program training (Children's hospital), the Medicaid coupon for seizure disorder which is covered under coupon; insurance covers some of this but lots of help from Medicaid and SSI. Teamwork of professionals from all the different individual case managers, King County- DVR, family member's vendor. Multiple meetings are held to discuss the challenges family member has faced by brainstorming solutions to these problems; have people answer calls and care about family member. Family member does not have the waiver, no transition funds; the county was able to access some money to help family member pay for that when he lost hours from first job. His second job was going to hurt his available outside earnings - almost provided a disincentive. Recreation program, cross organization collaboration are all working.
- P6:** A lot of things are working well. Maple Lane School offers cognitive therapy- aggression replacement training, mental help therapy. When he was in the community, the services that were helpful were "wrap around"- a team of professionals and natural supports that exchange ideas to work out assistive plans, team changes over time. Private insurance to cover medical prices, counseling, cub scouts, and swim club.
- P7:** Medicaid Personal Care. Our household has many different needs and MPC is the number one thing that helps the family stay together and cope with the rest of your life. Agency providers are awesome to work with; bill hours with case managers; co-pays are huge - saves a lot of money; pull up cost \$150 a month - went down a little bit.
- P4:** Do you need to be 18 to get Medicaid personal waiver?
- P5:** King County Parent Coalition - didn't know where to go for help before this, now there is another networking (WISE Family Networking). Parent connections through these have been very helpful.

Question 3: Is there anything you wish was different or could be changed?

- P1:** Respite is critical. If the goal of the state is to facilitate kids staying in the home, you can't take this away (decrease the service) but need to increase this. If DD kid comes in ER then they understand that he gets it; shouldn't have to be this way as a minimum group. Increasing respite resources and realizing this need; better understanding how respite can be received. Need to establish a well defined list of people. Maybe call a provider to have someone come out to house and have them assess the situation, establishing a well defined and accredited group of providers. If you need help, here is the list of people. Several of the group here have children with high functioning developmental disabilities, but this is not our case, so the interactions from other parents

who like transition programs don't seem possible. After our child is done with the school system it will be out of their hands and fall back into the parents. Where can we expect child to be after school? You are going to have to have coaching, guidance and help - feels like the program is focused around high functioning people or family members with DD.

- P1:** If the state is really focused on this program. then maybe the schools are not the only place to focus on these skills; needs to be more guided system outside of the bias of a particular school board.
- P2:** We came from San Francisco where my family member had been phased out of school. Some people cannot gain independence. She has multiple issues that are not diagnosed- both neural and physical disabilities; a very complex situation. She has medical needs that are not covered by coupons and no respite. The first care assessment was so low that I had to quit my career to take care of my daughter. With changing case workers, the budget goes up and down, and there is a lack of stability in care assessment. I used to be able to pay for respite care but have gone without for 4 years. We had wrap around services with Children's Hospital. When a person becomes 24 yrs of age, they send them away- the neurophysiologist is there, and there's a lack of these types of professionals that will see someone who is over 24 and who is dual diagnosed. Deterioration happens and it is really sad. There are strange loopholes around the adult population which makes it hard to have continuity.
- P3:** The "information highway" - schools are the way to start to get information. If you don't have a school district it is hard to know what to do. To me the first thing would be to get information earlier. Checklists of what to do before family member turns 18 are helpful. My son was denied by the waiver and I don't know what this means. I don't know what I don't know. You find little bits and pieces of information, primarily from schools since this is the logical place.
- P1:** Within the schools they resent having to do anything besides teaching: "It's not our job!" You will only get the quality that the school is willing to give in that school year. The case manager is great. Special education teachers are always changing; seems logical to have school be better.
- P5:** That is where the parent highways have been helpful; advocacy networks have been very helpful.
- P2:** SSI personnel worker in our county is very disliked. Can't change who does it, so these people are the only ones people can work with. They are limited to giving only certain information.
- P4:** It may be unrealistic to expect this from the school.
- P1:** If we are not getting support from the state what happens with the schools?
- P4:** Schools are already burdened. When our son ages, how are we going to care for him when he is done with school and doesn't have a full time job? He can be alone for 2 hours, but 6 hours? What do you do? What will his support system be? We are lucky at Shoreline because when he is at school, they have after school care. If you cannot be by yourself, where are the supports before or after school or work? You have to work it out between parents. Not everyone can do this and schedules change. Need a young man to pal around with son, hooking up with sports or activities with regular education population so that it's not just a special education but instead an inclusion. Building

these friendships can be one of the hardest things - can be difficult to develop these friendships.

- P5:** The friendship situation is clearly a problem. It felt like he was a part of the community during work - plenty of people to know and work with. He went from being a part of something to being at home when they ran out of hours and transition services. As a parent, I looked for ways to get him a job and volunteer experiences. He started out at 25 hours, but with business doing so bad it's hard to get hours. Things to get him to feel good about himself are hard to find. He wants more freedom - only help comes from within, matter of choices but therapy and medical expenses take away housing and residential supports. I feel stressed and overwhelmed with the new things that I have taken over with a full time parenting role without school system. It doesn't end when family member turns 21 - I'm spending most of the time trying to solve problems.
- P1:** I hope the information gets passed on to the Secretary (of DSHS). You cannot take care of a DD child and have a full time job. I've observed that it's a full time job; this is not trying to make life easier for people.
- P2:** You need to also take into account when there is only one other family member.
- P6:** I would add early detection and prevention, more education. There is still a lot to learn. A few things I'm hearing are the need for respite both in mental and special education, transition planning - needs to be more individual-based on long and short term goals with person centered planning, including sibling relationships. Services that child might need are there, but it needs a lot of work to see what lays outside of those that are known and how to actually go about doing this. Need to look at all the resources out there and figure out how to best apply it.
- P4:** It needs to be a collaborative spirit. Their child's needs in some cases are so great that it's so consuming they (family members) couldn't even make it to something like this here tonight.
- P5:** Intact families are still fractured by the many demands. People have to time schedule really well.
- P4:** There are classes to work with siblings, but there needs to be more.
- P7:** There isn't a lot of support with classes for siblings. You have to pay for counseling. Need to build a community for out of home respite. It doesn't matter what age, but we need to build community so that families can get a break. There should be more oversight by the state so the community can be built up and families would feel safe to take a weekend away. There also needs to be crisis care for families with individual who is very unstable. See what other states have done; don't want to have to put kids in an institution. Building community is the number one thing. There needs to be crisis care centers in our state so our families can be safe along with our family member. So they can get help and be brought back home afterwards.
- P2:** Had to go 8 years without primary care provider. Once you're outside of Children's Hospital, where do you go? There is a critical shift in their functioning and it can scare family members.
- P7:** There needs to be something more stable for individuals.

- P2:** More people are aging and need this service. The only way I got into this service was through pressing and to make sure it's not DD related or psychological and if there is no private insurance.
- P7:** It's the same for children - there are not good resources.
- P6:** Has anyone tried the Crisis Line?
- P2:** People with verbal skills can find help, but for people with developmental disabilities, there is nothing.

Question 4: What does it take for you to trust that community programs can support your child?

- P7:** Being connected with school district, I see there are many group homes for kids that work really well for children with autism. What does it take to trust community programs? I definitely trust what we have been working with, but we need options since we won't be around forever. There needs to be strong oversight to make sure that funding is going to the right place - to the clients. Whatever is working in kid programs needs to work in adult programs, too.
- P6:** Need to know I can get help when I need it; for example, in-home behavioral support. If there is a meltdown, how do we deal with it? I like New York's three-tiered system: can go to homes in the community.
- P5:** One of the things is that the information is inconsistent that we receive at meetings and from staff. Over the last 6 months, it's been hard to believe what is being said since its changing so quickly. I am worried about when I die and what will happen to my child. This is my biggest fear. He has no sibling here and what happens with guardianship. How can state or community help with this? I want to know that when I am on my deathbed that someone will be there to take care of my son.
- P6:** Isn't there a state guardianship firm?

Facilitator: There are private guardianship services.

- P4:** I agree with the same as what has been said, where we can find someone to take care of our children?
- P3:** Faith! It takes a huge leap - the kids want to do more when they turn 18. Personal involvement, everything he has done, parent jumps in to feel more comfortable and be trusting in the community. The community has to earn my trust.
- P4:** Part of why we get so involved is because there is not enough information. We want someone to pay attention to the child so that this can be told back so parents can know what has been going on.
- P2:** This is a hard one because I knew someone who had an adult family home and this was going to be the backup plan but she stopped along with a few others because of the economy. My daughter can't be left alone, even for a minute. To trust a program she would want Medicaid personal care person with her all the time. My daughter's disabilities provide for a high level of support and since it could not be said if there was support, care assessment would be very important in this way. An adult family home

with only a few workers on at night is a scary thing to think about. It worries me because she could not self-report abuse. Having institutionalized would break my heart.

Question 5: How could institution workers help people in the community?

- P7:** On the behavior side of things with psychiatry, it would be great if the workers could access this service. These workers could help in the community and don't need to just work in the institutions. SOLAs are one option for this. Spread the money around from and away from institutions. If you had more SOLA programs you wouldn't need so many institutions.
- P2:** I agree.
- P6:** When there is a transition that needs to be made, if the institution workers could help with transition plans to help people move out of RHCs. For anyone these plans would be very helpful.
- P7:** There's a program called Roads to Community Living which is helping the RHCs.
- P5:** If workers could go into community homes (to provide respite) and could keep their same clients or transfer to clients in better location - same efforts could be used only in a different setting.
- P4:** No comment.
- P3:** No comment.
- P2:** I agree with Participant 7. Therapists (at the RHC) could make services more available or do more trainings. My daughter greatly benefited from one occupational therapist.
- P5:** A parent in a King County Parent Coalition meeting said that there are some needs that can't be met by residential providers, so maybe someone can come in and provide these services.
- P2:** Especially if parents aren't there anymore.

Question 6: Looking into the future, if you could have three wishes for your son/daughter/relative, what would they be?

- P2:** Stability in SSI and Medicaid programs, include stability in medical and dental services, and eligibility for Medicaid. The continued MPC care being provided as long as it's needed in whatever setting. There is going to have to be some plan for the long term care for the aging DD community.
- P3:** For my son to live a safe and happy life surrounded by family members he loves; continued opportunities to learn and have new adventures; and good health. And then we've got it all.
- P4:** For friendships and opportunities to build these relationships, work opportunities to keep him motivated and active, and access to good health care. A plan for long term care would also really be important.
- P5:** A job that he likes and an affordable living situation that he loves with the supports to succeed. Friends are also key. Financial security for him so that after parent dies, he will be okay.

P6: Life skills that will sustain him after parents; to feel like a valuable member of community; and general health.

P7: Acceptance by the world; that he can work, and a good community placement. I don't want a burden to fall on siblings.

P4: Same goals as with any other kid, it is just harder to get to.

Question 7: Wrap-up: Is there anything else you would like to add to our discussion today?

P6: As a society we are moving away from institutions - a message that it is going to take a lot of efforts and we need to be willing to make these efforts; to give it the attention it needs and it deserves to make it work.

P5: Needs to be proactive not reactive. Safety net from institutions needs to be set.

P2: Want to keep the pressure on the state.

**GROUP 6: FAMILIES OF CHILDREN 31+ LIVING AT HOME
(REGION 6 FOCUS GROUP NOTES)**

April 30, 2010

Focus Group Questions:

Question 1: What services does your family member currently receive?

- P2:** Social Security/Support Medically (coupon), Supported Living.
- P4:** SSI Medicaid/private insurance, has own home with 24-hour care. Receives food stamps and supported employment hours.
- P6:** Has 24 hour supervision and lives at home. Have respite care when wanted. Goes to Tacoma Multi-Care which is an adult day care and must ride the bus to work.
- P7:** Lives in ITS house, needs 24-hour support, has DSHS/SSI/HUD and food stamps.
- P8:** Group Home, 24 hour support, SSI, Medicare/Medicaid.
- P10:** Has 2 sons. One has independent living, 8 hour staff and works a couple hours twice a week. The other lives by himself, works and is on Social Security.
- P11:** Social Security/Medicaid. Needs 24-hour care and receives food stamps.

Question 2: What is working well for your family member?

- P1:** Moving from Rainier School into the community. He likes it and is happy.
- P3:** Has been able to stay at home and has a decent program.
- P4:** Parent doesn't have to make quarterly doctor and medical check appointments or have to feed the animals.
- P5:** Highly involved in Special Olympics. Involved in the Abbey Players acting company in Olympia.
- P6:** A good case worker. She is wonderful.
- P7:** Lives with 2 others and she likes to look after them. They share the house well. Know she's safe with 24-hour staffing. She gets out in the community and takes work opportunities to do things during the day. Have a good social worker that will look in on her if we are gone.
- P8:** Has lived in the same home for 15 years; and if anything happens, the family is contacted. They can drop by unannounced, can go through records. The client has own room. Can go play basketball, wander around and is safe there.
- P10:** Does fine as long as parent is there to support him. The other has support from his home. We have training sessions weekly for our staff and have great care now.
- P11:** Doing well living alone and having 24-hour staff.

Question 3: Is there anything you wish was different or could be changed?

- P1:** Wish his home in the community had more space where he could walk around without having staff with him and be safe. His physical ability has suffered without the exercise. His work is at a thrift store, but is a non-paying job.
- P3:** Workers credentials and staff turnover. Wish they were paid more with more benefits so there was a higher quality staff. Wish there was more oversight of activities by the staff.
- P4:** Would like to see some repercussions for when the staff doesn't follow the client's plan or do the jobs they are contracted to do. Wish there was a staff that could communicate with her by signing. Wish staff were required to have a food handler's card and training in cleaning a household. Wish the agency would have a board meeting.
- P5:** Wish the provider could understand family involvement. Wish the providers, medical facilities and their staff as well as psychology staff knew what to do with a client who has co-occurring disorders and treated them better. Wish the staff at WSH followed the recommendations of the Allen lawsuit and placed client on the correct floor.
- P6:** Wish we could trust group homes to take care of her.
- P7:** Wish the providers would do what is in the ISP, specifically, cut her fingernails. Wish the right size diapers were kept at the house. Wish there weren't budget cuts so the owner could keep good staff to train other staff. Wish there was equality in schools.
- P8:** Wish the staff had better pay and benefits like they have at RHCs.
- P10:** Wish the psychology staff situation was better.
- P11:** Wish our agency would welcome input at a board meeting. Wish the medical facility staff were better trained.

Question 4: What does it take for you to trust that community programs can support your child?

- P1:** If staff were paid better, had decent training and was held accountable.
- P3:** If providers understood that monitoring needs to happen all 7 days of the week and full time.
- P5:** Have a friend who is an investigator.
- P7:** I wouldn't.
- P8:** Visit unannounced.

Question 5: How could institution workers help people in the community?

- P 1:** Maybe use them as inspectors.
- P4:** Perhaps they could share the medical professionals in the communities. They could do things in the county and help clients.
- P8:** If they could maintain their retirement and state benefits they could go to the community.

P11: Getting clients teeth brushed.

Question 6: Looking into the future, if you could have three wishes for your son/daughter/relative, what would they be?

P1: That my child could be normal. Would like to see our provider have more financial help for the facilities and make it possible for our child to be taken on excursions/activities.

P3: If there would be no staff turnover and things could stay the same as they are right now. Wish they would go with the ISP and take my child to church. Wish that there was as much money for facilities as there are for the prisons.

P4: Would like her to be healthy, happy and have a meaningful life. Would like her to be able to go to church. Would like her to be safe.

P5: I wish they could have everything that other people have, like the ability to be on the honor roll and graduate from school. I would like him to be someone's boyfriend. I would like him to learn how to drive and get his license. I would like him to not be told that he can't do things and there was no more discrimination. I want more support for families so that communities include them, fund job support and jobs where there are others similar to them.

P6: Good health for my child and us so we can keep her at home. That she could go back to adult day care and have something of value to do. I wish there were better trained staff in the hospitals.

P7: I would like for her to be stable, healthy, happy and equal. I would like her to enjoy the same things that we did and that she didn't even know she had a disability. It would be nice if she could get out and do the things that make her feel good and that would mean someone who could understand her and go out and meet people.

P8: Continued safety, health, dignity and be more engaged in life. When things are going smooth don't change it, like meds, etc.

P10: For him to be happy, healthy and safe. For hospitals to be better trained to deal with them.

Question 7: Wrap-up: Is there anything else you would like to add to our discussion today?

P2: Hope this meeting does some good with the State, the Legislature and the Governor. I wish they could experience what it is like to be disabled or what it is like to care for someone who is disabled.

P4: I have anxiety over my kid having someone to take care of her after I am gone.

P8: We are worried if they will have a home and who will take care of them when we are gone.

**GROUP 7: FAMILIES OF PEOPLE WHO ALWAYS LIVED AT HOME
(REGION 1 FOCUS GROUP NOTES)**

April 16, 2010

Focus Group Questions:

Question 1: What services does your family member currently receive?

- P2:** SSI, DVR, para-transit, MPC
- P3:** Soc Sec, Medicare, Medicaid, para-transit.
- P4:** Same as P3.
- P5:** SSI.
- P6:** SSI, Medicaid (big piece), PACE, Spokane Falls Community College, bus training program, MPC.
- P9:** SSI, MPC, Respite, Medicaid, dial a ride, job trainer, para-transit.
- P10:** SSI, Medicare, DVR, Pilot program/Skils'kin, DSHS food stamp, HUD sec 8.

Question 2: What is working well for your family member?

- P2:** I came from Snohomish County after 17 years. Better service in Region 1. PACE is good. DVR slow but overall good. Wonderful case worker, very wonderful and responsive.
- P3:** Same as P4
- P4:** Didn't get with DDD for quite a few years. Lots of things going already. DDD very helpful, same with para-transit, good service.
- P5:** DDD up until last 2 years, so many case managers. One we have now is wonderful; she made up for all the rest. Just call her, she's great, she keeps me on the line.
- P6:** DDD doing great job, keep switching case managers. Each one follows through. Went to all IEPs, helped with transition. Happy with Spokane transit, PACE college program. High school great experience- Mead HS.
- P9:** Case manager is great; he will be retiring soon within next 2 years. Both CRMs went to IEP meetings in school; school not always happy with that. CRM helpful accessing services for her support so mom could work part-time.
- P10:** DDD has been life saver, had lots of issues since moving to Spokane. SSI assumed cured so benefits terminated. CRM has been fabulous. DVR was great, now can't work, county hasn't determined he's eligible. Section 8 messed things up, had to start over. DDD has been wonderful.

Question 3: Is there anything you wish was different or could be changed?

- P2:** Met my new case manager. Funds that were attached to employment from Snohomish didn't transfer from Snohomish County. Funds attached to her to live in own home with others. If you go to an adult group home, you won't do any cooking or laundry. We've been working with her on this for 20 years; this is a step back for her. Ought to be a way to help her with those funds in a living situation that isn't so restrictive but would help her. That's my only big gripe. She's not ready for moving out yet. Haven't explored what else is available, yet not quite ready. System is set up to not pay things out. Make people aware, it's process of discovery; they don't make effort to tell you. System set up to not tell you, what's out there, what's available. Medical coupon on card; state is a big waster of paper. Every month get invoice to call in hours. Then another piece of paper comes. Was in foster care and adoption system before. With contracts, you get 2 or 3 notices. To save money stop with sending out so much paper.
- P3:** Case managers seem to be temporary. They move on, so why get so involved in client? I want them to get more involved and informative. Want more consistent case managers/stay with them. I would like my son to be normal. Like him to get out and work but with brain surgery and damage it's too tough. 45 surgeries, doesn't remember what do to next, forgetful.
- P4:** Same as P3.
- P5:** My daughter just now qualified for respite. That's new, now just getting it; don't know what to do with it. Just learning how to do that now (manage respite). She has job, but not getting paid. I found a volunteer job for her 2-3 days week. I'm lucky to have a friend who works in a tech center. In high school we didn't need respite, and then we got a call saying we get these services. My daughter was picked for employment, but she also needs a personal caregiver, so she can't do it. I had to send caregiver to work with her. Seems like lots of colleges teach special education teachers; seems they should take course in community services. It should start way before graduation. If teachers had known, they could help funnel them (to services). No case workers involved until high school. The state sends letters to clients that people can't understand. Should call them or send someone to tell them.
- P6:** Transitions dollars and dollars supporting job training. Got a call from Olympia DDD in the fall, but at the time we didn't need funding. I said he didn't need it in high school and told him to take it off. Wasn't informed at the time. Transitioned out at 21 last year and no transition dollars available. No flexibility, made huge mistake by saying we didn't need services then; should have taken them then. Most things you learn from other parents, not case managers. Felt we didn't need the dollars at that time, but when he becomes an adult we need it. We'll set up housing with our own funding. The system is set so you don't know things; don't know what you are answering questions to, so you don't get things. Teachers can explain school services. State doesn't have a handle on their services, no parent educator to explain services, don't understand terminology. Things get dropped until client is adult and everyone is involved. ARC is helpful. My son did a pilot program with Mead for employment, but funding ended so it went nowhere after school. Schools don't want to be legally responsible for giving information. Should be giving information out in the beginning, not waiting until high school.
- P9:** Parent coalition can help with educating parents. DSHS sponsored coalition. My path a little different. I live in another county and am involved with the DD County Board. Changes in last 5-10 years, concentrate on waiver system. When it first started, it took in everyone, no criteria for who needed it. Legislature, budget just came out, opening 439 new slots in waiver. Kids graduating, encourage other to re-apply for waiver for

employment. Criteria has been inconsistent, high functioning with own cars are on waiver. Should be for more disabled. State should go back and re-evaluate. Need to look at institutional piece vs. community. The institutions support less than 5000 people in institutions with large part of budget. Little discussion of closing institution. Should be using beds in RHC for community folks needing medication changes. Work to develop AFH, SOLA, SL within community where individuals live. Sometimes there are problems with the caregiver's inappropriate appearance and my daughter is embarrassed to be seen in public with her. Reduction in MPC hours to balance budget. State going through lawsuits. MPC captures federal match. Can't change those unless re-assessment. If lawsuit prevails, DSHS says dollars will be taken from other vulnerable persons. Take dollars from most vulnerable and least vocal. I wrote letters, they said just trying to balance the budget. DDD doesn't recognize mental challenges our people have sending paperwork out to client and guardian. Even guardian doesn't understand sometimes.

P10: Involved in parent coalition in Seattle but not in Spokane. As far as DDD, high turnover in Seattle area, very frustrating. Not a problem in Spokane. Access to care providers; have issues due to transfers lifting, etc. Finding care providers with new HIPPA rules, even with referral agency, not very helpful. If care providers could sign release, saying I'll work with this many clients. Used to get list with name and numbers but at least we had a list. Case manager helping me with work issue. Trying to get in pilot program to get out in community. Some clients cannot go out in the community when they are incontinent or have seizure, memory, and/or behavioral issues. This week my son is no longer in workshop, doing volunteer work. Her son would be unhappy if he knew he wasn't earning money. He's in Pathways to Employment, applications to Seattle; why would they do this. This is just filling in space so we can get our \$575 from DDD. It should be behavioral ability appropriate. It doesn't work for everyone. County trained job coach and agency to learn how to search for job. Two managers never got copy of report. Representative from county came to last meeting, reports weren't given by trainer. Family gave list of places to search for jobs, volunteered to be there to help and adapt anything. Agency did nothing and didn't follow through with plan discussed with report no one got.

Question 4: What does it take for you to trust that community programs can support your child?

P2: We'll be involved. Worked in social services in early 90's. Had client abused by staff. It was a good agency but it happened anyway. You can trust any program; you just have to stay involved so they know someone is watching. Avenue to be investigated by parent coalition. Case worker always overloaded. Unrealistic caseloads. Can't expect system to work well if overloaded.

P9: Unannounced drop in visits are important. Some groups starting in state to be guardian for others. State shouldn't be guardian. CRM travel long distances, unrealistic caseloads.

P10: Scary thing, if parents not there monitoring. Child will outlive parent. Assigning second guardian is scary thing. Then rely on state to take care of them. I think unannounced drop in more often, do serious background checking, reference checking. Have had other clients live at my home when they leave AFH short term.

Question 5: How could institution workers help people in the community?

P1: Staff have an incredible knowledge base; could use skills to help people get jobs.

- P2:** Big gap: employment for people with disabilities. Get jobs, and then lose them. Real need for help. These people have incredible knowledge base about DD. Use that to help folks get employed.
- P6:** DDD: help employer and school. DDD needs employment specialists to develop relationship with school and employers. Para-educators go with students, only have so many hours. Can't put in time researching job sites. Need community awareness for employers that there are students needing jobs.
- P9:** Use RHC for respite, medical personnel/change in medications; instead of going to hospital, go to institution. Use in community placements, group supports, develop jobs in institution, use that expertise in community. More SOLAs. Re-use the staff in communities to promote more involvement and hold communities responsible for taking care of all, not just typically developed. Schools aren't always realistic for what jobs persons with developmental disabilities can get. Parents must be proactive holding schools accountable. Use institution staff on not only help to get job, but how to manage behaviors. Heard of groups willing to be guardians - an avenue that needs to be looked into.
- P10:** In Kenmore, teacher and DVR were great. Got son job. Use parental support.

Question 6: Looking into the future, if you could have three wishes for your son/daughter/relative, what would they be?

- P2:** Meaningful employment, independent living situation that works, boyfriend that works.
- P3:** Get the same care that getting at home, better access ramps into homes of others - more accessible world.
- P5:** Hope her brother will be guardian, hope she marries someone who likes her; hope someday people will see her and not her disability.
- P6:** Meaningful employment; independent living that works; reach his full potential - wasn't supposed to live, every year they give us 1 more year.
- P9:** In process of changing waiver to supported living; live as independently as possible. Requested RHC placement in order to get SL placement, didn't want RHC but had to go this route otherwise no Core Waiver. Moving into SL May 1. Also, live as full a life as possible. True for all children.
- P10:** Ditto. Had to call in friends and relatives for help. It's scary, knowing what's out there; with some homes it is even more scary. Why can't parents or guardians determine where individual goes? Why does state say they have to go here or manipulate the system to get what you want? Huge emotional thing for parent. State is not working with parent to help with this. Quality independent living and meaningful job.

Question 7: Wrap-up: Is there anything else you would like to add to our discussion today?

- P6:** Roadblocks-school, DDD, courts. No one to lead you through all of this. No one cared about us until he was 18. So we had to go and get guardianship so we can stay in his life. ARC is helpful educating about need for guardianship. At age 14 the state takes over medically making decisions.

- P9:** As parents we have to fight every step of the way. Choice would be for children to have no disability; however, when they do, there are so many roadblocks from school. Guardianship is paramount for medical decisions. Schools tell families about age of majority. Should give out information about guardianship at age 17 with the IEP.
- P10:** There should be a choice of homes for family. When he first left rehab after 2 years, it was nightmare, no legal definition of brain injury, no help. Looking for resources for brain injury. Somebody should have given them the information to tell them there's DDD, DVR, etc. Parent dealing with all this stuff, disability, DVR, school, etc. Olympia sits and waits for you to give up. Had someone teach me about what is needed. Sitting in DDD parent caregiver course. Many parents don't know they need guardianship.

GROUP 8: SELF ADVOCATES LIVING IN THE COMMUNITY (REGION 4 SELF ADVOCATES FOCUS GROUP NOTES)

April 14, 2010

Focus Group Questions:

Question 1: What services do you currently receive?

- P1:** Social Security Disability, limited to how much I can earn before losing benefits.
- P2:** Services through the ARC worker helps with home tasks, subsidized housing through Section 8. When I was 18, my mom tried to help me apply for SSI and they wouldn't help me while I lived at home with my mom.
- P3:** Social Security Disability, in line for Section 8 housing.

Question 2: What is working well for you?

- P1:** Working is working well for me. It is satisfying, have a rich family life; in general things are just good. Happy with the balance I have in my life and it is important.
- P2:** Have a lot of daily crisis, but life is going good, I accept things and kind of live by the model of accept what I can't change. Just lost my parents a couple of years ago but I have a strong family base.
- P3:** Life is good, quality of life, being involved in the things such as working. Getting acquainted with Seattle. Figuring out things and forms, SS stuff, other things coming to me that my mom is trying to help me with. I do have the scenario of what if my parents died, and I am disabled, what is going to happen, how stable, how can I have a good life, be strong enough to transition to my situation? I moved here as an adult and have lived in this state since 2007. It is good to be young adult, doing the ARC, doing this meeting, then go home and put on SpongeBob pants. Lost my grandpa several years ago and he was my good friend.

Question 3: Is there anything you wish was different or could be changed?

- P1:** Transportation - Access: I have to use it and it is not reliable and it is humiliating. I would work more if it wasn't an issue all the time. It takes the spontaneity out of life. Must be planned at least a day in advance.
- P2:** Yes, it is also the same for me. I take the Metro occasionally and it doesn't go everywhere. My medical transportation is great. Took me 2 years to figure it out. I use a transportation coordination agency and it is great. I am a kidney dialysis patient. Every time you have a doctor appointment, they get you there in plenty of time, but they don't care about the person much. I do Cabulance and they don't work on Sunday. I'm getting there way too late for my dialysis and I only have an hour of daylight left. A doctor appointment is different than a dialysis appointment. Navigating the system, such as SSI and all the laws. I am on Medicaid and all the laws that go with that. I wish SS would send a letter that uses better terminology. I feel guilty because I am tired and wish I could work more but the dialysis keeps me down. I do a lot of volunteer work. Someone told me that volunteering isn't employment. It makes me feel bad that I don't have a paying job and I don't pay taxes. My dad worked his way through law school and

college. I said I hope you aren't ashamed of me that I don't work. He said he was glad that his taxes did something good. You always get a letter in the mail.

- P3:** People in the community having better respect, less labeling. Am concerned about losing some benefits due to working. My mom is having trouble understanding that. It is the process that is difficult. My mom doesn't understand why. My mom gets a letter in the mail and she tried to get it.

Question 4: What does it take for you to trust that community programs can support you?

- P1:** In order to trust in the community program, the person would have to have understanding that they should want the person to succeed, not be so cold. Not make the requirements so tough that you can't get in there.
- P2:** Someone told me the State was going to inspect them more. Think they need more oversight for the safety of people. My son is in an AFH. The first one didn't work out because the wife said he was taking too much time to adjust. He was in a much more structured environment before going there. It takes so long to license these homes. He moved to a different one, is much happier, and has less tantrums. Give people time to adjust.
- P3:** Making things easier for people with DD to understand.

Question 5: How could institution workers help people in the community?

- P1:** Don't know why they couldn't do the same work in the community that they are currently doing in the institutions.
- P2:** The way the Developmental Disabilities Council says there are 2 main problems: they keep us in poverty and keep us segregated. The institutions just warehouse the people and that is wrong. There was a bill that didn't make it this year which said if a person moved out, the worker they had would work with them in the community. This way the person would have the same services. Would still get the care but in the community.
- P3:** Must do all the same stuff all the time and eat the same food. I like this bill about the institution staff too.

Question 6: Looking into the future, if you could have three wishes, what would they be?

- P1:** I would like Access to get their act together (transportation). The differences between people would not be emphasized and the commonalities would be emphasized, and financial equity would be better. I feel discriminated against at times, and am treated as I am less valuable.
- P2:** No labels; would like to fall in love again; and no color blindness between people or racism. Wish I could teach this to my son. What color a person is doesn't matter. Treat people equal. Trying to get him to use the terminology better. Discrimination I do feel. Like going to a restaurant and having the waiter ask the non-disabled person what the disabled person would like. The bus used to be for the elderly or disabled, but now with gas being expensive, it is getting more equal.

P3: Wish people with DD could live the same lives as anyone else; that homeless people could receive the same lives as anyone else. If I had a million, half would go to nonprofit organizations. With the other half I would buy something big like a really cool black leather jacket. Pay more attention to people with disabilities. They do stuff without even asking us to see if it works for them. We feel we are discriminated against. Having total access to things we would like to have, don't drive but rely on buses a lot. Understanding services, we understand some but not all. Who is really going to give some attention to us by giving large print for those who need it?

Question 7: Wrap-up: Is there anything else you would like to add to our discussion today?

P1: I think it is good you are doing this for us. The issues are being recognized.

P2: I am glad you brought up transportation; among advocates it is the number 1 complaint. It never showed up in the council's surveys. They were surveying people who live at home so the issue didn't come up very high. Sometimes you can be on a bus for hours. Late to meetings. I was picked up early, but they had so many drop offs to make I was late. I asked when we would arrive, but the bus driver told me to chill out.

P3: Some people miss meetings due to transportation issues. Hate missing the first parts of the meeting. There is no way to make the portions that are missed up.

**GROUP 9: SELF ADVOCATES LIVING IN THE COMMUNITY
(REGION 5 SELF ADVOCATES FOCUS GROUP NOTES)**

April 27, 2010

Focus Group Questions:

Question 1: What services do you currently receive?

- P1:** AFH Services through DDD.
- P2:** Supported Living agency. Transportation, errands, grocery shopping, doctor appointments. Also have a case manager who works for DDD and does waiver services, home visiting.
- P3:** Wife has HCS person to take her shopping. I have a DDD case manager, receive Basic waiver and work. I have a job coach.
- P4:** MPC Provider who is my mother.
- P5:** Am a DDD client with no services.
- P6:** Supported Living, transportation to doctors and grocery shopping. Residential providers.
- P7:** Supported living agency. Residential services, grocery shopping to whatever I need to have done.
- P8:** My supported living agency helps me and I am on the waiver.
- P9:** I receive all help from DDD and live in own home. I have a residential program with people who help me.

Question 2: What is working well for you?

- P1:** I get to go out wherever I want and they treat me as one of the family. I like the people. It's like my own place. I don't have a curfew, just shouldn't stay out all night.
- P2:** I don't have a job yet, but I have a person who comes to my house and we work together. She helps me pay my bills and she answers her phone messages. She takes me to the bank, grocery shopping. The agency has a lot of staff and a 24-hour service. I like the staff.
- P3:** My employer is helping me out really well and that is where I work. I have good hours and I have flexibility to go to all my meetings.
- P4:** Everything gets paid and I know where the money is going; my mom is my helper.
- P5:** My new apartment. It is in a good location, near the YMCA. My exercise and my own diet.
- P6:** I like my job.
- P7:** I like my apartment. When staff are on time it works well for me, but they are usually late. I like my apartment.

P8: I have a caregiver and they help me with shopping and appointments. Sometimes staff cancels appointments. I want to live near my mom.

P9: All of my staff at the residential program.

Question 3: Is there anything you wish was different or could be changed?

P1: Nothing, I do my own thing. I have problems with the shuttle bus services. It's a big hassle. Would like to go someplace without having to call my parents to come pick me up. I have to take 3 buses to get there. There are no bus stops where they live.

P2: No. I get along with the person who works with me. I'm happy and always in a good mood.

P3: That we could change the "R" word (retarded) and use People First language! Should be a law that you can't use that word. Should get rid of that word fast.

P4: Worried about my mom's cataracts in her eyes as she may not be able to drive me anymore.

P5: My negative attitude - wish I had a better attitude about everything.

P6: I want to go see my brother in Tacoma and it is hard to do.

P7: I would like my staff to ask me what I want and not make choices for me. I would like my staff to be on time. I would like the politicians to listen to us and give more services if they increase taxes. I would like them to walk in our shoes. We need transportation because without it, we cannot have a job.

P8: I would like to learn how to make my own decisions in case something happens to my mom. I would like staff to teach me how to clean and how to have a job.

P9: I wish the shuttle transportation service was better; they are cutting services. It has been cut off and it makes it hard if you work and need to get around. I would like medical professionals to talk to me and not my staff. That's a problem for a lot of people. The bus driver thinks that I shouldn't be by myself. I would like them to not cut our services.

P7: Budget cuts—how are they going to affect people?

P1: It's going to get worse before it gets better. States not covering certain things.

P7: It's going to hurt people with disabilities. If there are no buses, you can't do anything.

Question 4: What does it take for you to trust that community programs can support you?

P1: Trust is a strong word. I have a hard time trusting people. They talk behind my back. They let me down. Not happy with the State as they are changing a lot of stuff and it is harder on the residential workers and it is costing us money. When I had my own place, I had to trust people working for me. I hear so many things that people who work for the disabled steal from them a lot.

P2: No comment.

- P3:** Certain people have been lying to us. We had to fight for all we have gotten. I would like to see them do that too.
- P4:** My case manager is setting things up for me for when my mom can't take care of me. The workers aren't paid much and they steal from the clients.
- P5:** I got out of the residential program because I feel they lied to me. They said they would help me with all these things and didn't. Trust goes both ways.
- P6:** That people do what they say they will do.
- P7:** For them to be on time and don't make other plans. And tell me where my money is going all the time. Right now I have to wait until I see them if I want to buy something. I have to be able to count on people.
- P8:** I don't like them cancelling on me all the time at Northwest Living. When they are on their way to my place, their boss tells them to go take other clients for staff that don't show up, and they cancel on me. The other clients get more hours than I do.
- P9:** It takes a lot. Trust is a very strong word. I can't get my money out for my work. I have to trust others to do it. They have stolen from me but it hasn't happened lately. Now I go to the bank and have them help me with my bills.

Question 5: How could institution workers help people in the community?

- P7:** If the staff wanted to help clients in the community, they would have to get to know us out here. I want to make sure I can trust them in my home.

Question 6: Looking into the future, if you could have three wishes, what would they be?

- P1:** The State would look into problems like transportation to see where the funding is going. What are they using it for? That someone would do something about people who are not respectful. What are they doing about staff stealing from us? I fear the funding being cut, and how will the workers get paid? People like us will be stuck.
- P2:** No comment.
- P3:** Give the people that we work for more money. Give the handicapped more money. I would like to see the legislators do what we do and live like we do. Nobody should be so poor that they have to live out of garbage cans.
- P4:** Give money to keep kids going to schools. Pierce Transit not cutting the routes out.
- P5:** I wish I was seven years old again because then my parents had to do all the worrying about stuff. They were both around then. I wish we had a better service for the disabled and everyone else and better jobs. I wish I had better respect.
- P6:** Get a good job.
- P7:** Politicians need to look at the programs they keep cutting and that the Governor doesn't raise taxes. I would like to meet the President and give him an ear full. I am concerned about kids dropping out of school.

- P8:** I want the politicians to quit cutting programs; don't know who to trust and to vote for. I would like to learn how to make decisions on my own.
- P9:** I would like more hours of support. I wish I could work. I wish I could have more physical therapy.

Question 7: Wrap-up: Is there anything else you would like to add to our discussion today?

- P3:** Tell the DDD Director not to cut the budget.
- P8:** Same.
- P1:** Same.
- P9:** Don't cut programs and transportation.
- P5:** Don't cut the buses or the shuttles.
- P8:** I would like the Director of the Division of Developmental Disabilities to walk in our shoes without cars or anything. When we want to go somewhere, we have to scrape money out of our own budgets and without transportation, we can't go anywhere.

**GROUP 10:
FAMILIES OF CHILDREN ADMITTED TO RHC WITHIN LAST 5 YEARS
(FIRCREST SCHOOL FOCUS GROUP NOTES)**

April 17, 2010

Focus Group Questions:

Question 1: What services does your family member currently receive?

- P1:** School, help with medication, balance to help with behavior and recreation.
- P2:** Safe environment, medication support if he needs additional restraint, school, recreation. Learning new skills, maintenance help when they break things.
- P3:** Excellent medical care; 2:1 lots of times, someone with him all time, go into community; safe here - lots of space here; needs to be able to walk around, gets aggressive if he is in smaller spaces.
- P4:** Immediate wrap around services, great psychologist, behavioral specialists, medical doctor; can get quick response; dental; therapy; less stressful here; more professional staff - compensated better.
- P5:** Here over three years. Safe environment, requires behavior management; behavior is under control here; constant routine here - impossible to do routine same routine at home; wrap around services here; medical.
- P8:** Fircrest is a home away from home; learning new skills; helps his self confidence, interacts with people in more appropriate ways, grown in the last few years.
- P9:** PAT N: She has medical needs, not behavioral, wrap around services. Gets everything she needs; gets constant medical attention that is immediate, medication, OT, PT. Nursing is right there and people understand her needs immediately. She will never have a job. Gets recreation she likes, safe here, trusts staff completely. There is no staff turnover; group homes have constant turnover.
- P10:** When I take her for the weekend I get medications and good support. There is parental access.
- P11:** Echo that - staff turnover is fairly low; access to medical providers, work skills, safe place, the environment is good; he likes it and he seems to enjoy living here.
- P13:** Shoreline School - last year attended on campus, right medication after 9 years, PT/OT here and at school.

Question 2: What is working well for your family member?

- P13:** Knowledge of doctors and psychiatrist that are here regarding dual diagnosis; hard to find in the community.
- P12:** Interdisciplinary team approach, health care professionals here, instant response to medical or behavioral crisis, transition to public school, still needs constant support; he's happy and we're happy; campus physical support, space between other people.

- P11:** Get good feedback from staff if something comes up with medical.
- P9:** Still adjusting to her living here, everything is working great. Familiar with staff as I used to work here, trust everyone here. My daughter cries a lot; I also know she is happy when she doesn't know mom is here.
- P8:** He trusts the people around him, helps him get better.
- P7:** My son likes to ram things with wheelchair and has enough space to move around. Immediate response was to put someone with him to keep others safe when he likes to ram wheelchair. Good communication: I get a call if he gets Tylenol; happy here, likes me to leave sometimes.
- P5:** Medical support – Interdisciplinary team approach, many opinions coming together, constant routine and structure; he's happy, his life is better here by 100's of percent; have access to our kid.
- P4:** System failed him, ended up in criminal justice system and at another facility; got here and found people who understand autism, could not get this care anywhere else; doing better than he's ever done; constant immediate communication has been great, paying attention to us and made all the difference; access to our kid, we can come to unit whenever we want (group home wanted to know ahead time).
- P3:** Our son is non-verbal and aggressive. Medical wrap around; Harborview Medical Center, Children's Hospital, and other facilities said they couldn't help him. He is doing the best ever since he came here.
- P2:** Fircrest is a nonprofit organization. You have to have severe issues to be here. This is like heaven. He was in an institution in Reno before he came here; he has made leaps and bounds since he came here. There is enough staff to keep him safe and live his life; this place is heaven--he's doing wonderful.
- P1:** Quality of life has improved. When people work their shifts they come in refreshed, can't do that as parents. Staff are so consistent, helped my son, medical and behavioral. They look at things longitudinally; long term view of data is very powerful. Fircrest is flexible; we see our son every week since he's been here, nice ebb and flow, likes to go on van rides, big deal for him.

Question 3: Is there anything you wish was different or could be changed?

- P2:** Get pool back; these services are mandated; these are the most severe kids.
- P5:** Get pool back, get funding, our kids are not less than; can't keep cutting money from the most vulnerable; my child life has gotten better, parents lives are better and our other children's lives are better; what works is Fircrest.
- P4:** Get pool back; my wife goes Olympia - know that Fircrest will close in 2012. Organizations that help handicapped kids want the money, our kids need this care; keep them out of criminal justice system, giving our kids a death sentence. We're involved in the political process and this closing and cuts needs to stop. Our son can't come home; group home staffs are not as good as Fircrest staff; with group home staff we had to do a lot of medical, etc. Group homes cutting back on food; refer to them as their daily rate. Told by ARC and DD Council that their needs don't matter, only higher functioning needs. Closing Fircrest will put all the pressure on criminal justice system; it will cost

you big time with lawsuits if Fircrest closes. I don't understand why it's so hard to see that our kids require more because they are the most severe; we had to go through hell to get our kid to Fircrest – we were told it was closed.

P9: Dismantling of programs throughout the years. Can't drive more than 5 miles; closing of cafeteria. ARC's definition of severe is different than mine - severe to them is mild, my daughter is severe. ARC didn't have services for here.

P6: Freedom of having a normal life.

P11: Staff are well trained.

P3: Group homes have right of refusal; son ended up with PTSD. Would like the ARC and Disability Council to go away, stop wanting the land, refer to Fircrest as the DD Land Trust.

P12: ARC support groups did not represent me or my child; only concerned about their higher functioning kids, all we had before we got here was emergency rooms.

P9: DRW (Disability Rights Washington) said that they don't represent anyone at Fircrest, don't advocate for clients at Fircrest.

Question 4: What does it take for you to trust that community programs can support your child?

P7: Create another space that is 10,000 sq feet or a facility for medical fragile.

P3: Can't tell your neighbors not to honk their horn, slam doors. Don't trust DSHS and DDD -need an audit.

P5: Kept at home as long as possible; then came here. I would need to stop seeing bad things in the news, like fiscal abuse, mental and physical abuse, and rapes. I know that they can provide the services here. Would have to have short shifts for staff to stay refreshed and be able to work effectively with the kids.

P2: Life time guarantee, camera monitoring system.

P4: DSHS is not capable. There would have to be wraparound services that are verified, professional oversight, and promised current level of funding. It's because of here that he is doing better. Our kids will likely need to come back for a tune up. If he moved out; what happens if Fircrest closes? Where do our kids go? Oversight poor in group homes; when people are making money off our kids, they cut back to make profits. People who cut pool had no idea what it meant to our kids and the community. Enforce regulations and provide oversight, provide medical/behavioral wraparound services; put RHCs under Department of Health. Need something that is integrated - communication and all areas working together.

P13: Same as Participant 4. RSN and DDD were fighting about services, had to leave daughter in emergency room to get DDD to do something. Moving daughter out after three years because she is stable here. They are matching daughter up with a housemate currently - recreate in the community, will live with one other girl. Interviewed 5 different providers, chose group home that is a good match for daughter. Will continue to go on community outings with new roommates, once we determine that

she likes her roommate, I will ask my daughter if she wants to move, it will be her decision. I was promised that my daughter can come back to Fircrest (if it doesn't work).

- P9:** All her life we searched for respite - respite providers didn't want to take her or took her once and then said not again. It's cheaper to have her here; not one group home I would trust. They don't have the medical backup, group homes would need a whole lot of money with a nurse on staff; used to provide services of OT,PT, speech to group homes; would find staff would not be on site; English was not understood very well. At Fircrest if there is a language barrier then there is back up.
- P10:** Institution memory.
- P2:** He needs the onsite maintenance staff to repair items he destroys. He's a runner and has the space here, doesn't have skills to be in the city. Cheaper to have him here with the cost benefit; here staff will switch.
- P8:** Agency said he would have to have his own home with 4 staff; I said that's not going to happen. Sometimes communication barriers with staff with son and parent.
- P3:** Neighborhood crushed when pool closed.
- P11:** 24/7 access to kid; financial audits of provider; standards of care so staff have clear expectations; mandatory training; no planning to get economy of scale.
- P1:** Medical and psychological, long term data keeping, quality of people providing direct care services. Don't trust a house is the answer; if kids were in community in a small setting, they won't have the staff to meet needs.
- P12:** Multiple disciplines to respond - we just described a RHC.

Question 5: How could institution workers help people in the community?

- P9:** Used to send Fircrest staff to community group home which worked well. Some staff couldn't speak enough English to communicate.
- P8:** Sometimes communication barriers here, but there is enough back up.
- P5:** Staff and professional staff could be a great asset to the community.
- P9:** Clients could receive special services here.
- P4:** Parents have to be at wit's end, crisis to get any help; respite doesn't work for autistic kids.
- P10:** Staff could be the police?
- P9:** ARC has this fantasy that everyone is going to have the same kind of life; most people with disabilities don't need to live here; people are being denied respite services.
- P4:** You have to remember what happened to mental health in the 80s when they deinstitutionalized.
- P2:** In Reno I had to fight, call the governor, abandon my child to get services, and hope for a good judge.

P5: Caseworker had to be almost attacked to get son in here.

P7: Having respite doesn't mean it is going to help when he comes back.

P8: Fircrest saved his life.

P5: Our lives, too.

P3: Bought homes for our kids - DSHS and Shoreline School District broke it up.

P8: Fircrest School is wonderful.

P13: Why does DDD lie?

Question 6: Looking into the future, if you could have three wishes for your son/daughter/relative, what would they be?

P14: Leave Fircrest open; make it be available.

P13: Job, get married/relationships.

P12: To always be in a safe environment and receive critical resources to survive in a facility like Fircrest (only place we have found); stable source of funding for Fircrest; and ARC stop saying they represent him because they don't.

P11: Get a stable resource - open pool and cafeteria.

P10: Parents wouldn't have to put so much energy into keeping Fircrest open and sustaining her program.

P9: Safe, happy and healthy; and living with people who understand what makes her happy. Need to be thinking ahead about how to support all kids that will be graduating from high school; need to make sure medical fragile kids don't die.

P8: His frustrations would be minor, job to make money for cell phone, be happy in whatever he is doing.

P7: Safe, healthy and happy, and that he would have experiences that are appropriate for him.

P6: Safe, someone always there, active, working, trips into community, and a cure!

P5: Be here, general health and happiness, and that he reaches his potential. Continued funding for my son and others to be at Fircrest. That people in Olympia understand our kids are not less than others, not throwaways. Decision makers need to see reality, not dollar signs behind them. What happens what we die? Autism numbers are on the rise until a cure is found.

P4: Safe, healthy and happy. I'm pushing Fircrest to use a letter board - he is not allowed to use a letter board on his unit - reach his full potential.

P3: Happy, healthy and safe. That he will always have continual care, no matter how old he is. I fear that he will end up in jail, prison or jail; he could get three strikes and he's out.

P5: What happens when we die?

P2: That he be valued by society, prayer for him that his spirit is calm, be at peace and be here at Fircrest.

P1: Peace of mind that he will be well cared for when we are gone, people continue to work with him and he can continue to develop. That he not be in the middle of these political turf battle over resources. Will need centers like this with the number of autistic kids being diagnosed; look ahead to plan for the number of kids with autism.

Question 7: Wrap-up: Is there anything else you would like to add to our discussion today?

P1: Important for lawmakers and policy makers to know what crisis truly looks like. Video imaging might be very helpful to see what it looks like when my kid and others lose it.

P9: Told daughter was going to die. Daughter survived because of me. DDD talks a good game. Most of us have other kids; we need help, for example, counseling and support. There is a high rate of divorce. No help for parent and other kids counseling would be helpful. Other daughter is going to get Master's in disability policy - she knows disability.

P11: What are they going to do with all the autistic kids?

P1: Can the next study indicated in the supplemental budget include this information?

**GROUP 11:
FAMILIES OF ADULTS ADMITTED TO RHC WITHIN LAST 5 YEARS
(RAINIER SCHOOL FOCUS GROUP NOTES)**

April 24, 2010

Focus Group Questions:

Question 1: What services does your family member currently receive?

- P1&P2:** Impressed with health and medical services. My brother is 60 years old and had a hip replacement shortly after admission and he is doing much better. He is on a lot less medications than when he came. He has speech therapy; before he was difficult to understand and not talking a lot. He has made major improvements and is much more social at Rainier School than anywhere else he has been. He gets bored easily and the activities here are helpful.
- P3:** My daughter is 25 years old and receives medical care, psychiatric and behavioral support, and vocational opportunities. She receives everything the community couldn't give her.
- P5:** She receives psychiatric services, medical care, and is safe. She used to be in Intensive Tenant Support (in the community) which failed us. She is now in a stable environment.
- P7:** Our daughter is 41 years old and has two jobs. She is safe and receives psychological and medical care. This is the best place ever.
- P8:** Rainier school has provided better control of our daughter's medications - a "skilled attack" on her medical needs. There are skilled professionals working together to meet our daughter's medical needs. Rainier is the stable living situation that has not been available. Group homes were not successful; I can't imagine her being anywhere else. She loves her work opportunity. In the community, work is almost impossible to find. It is extremely helpful having her here; there is better communication and she gets better help with hygiene and training.
- P9:** My sister came 4 years ago for respite care via a psychiatric ward and Yakima Valley School. She could not walk or feed herself. Her medications are stabilized and she is walking now. I like the fact that my sister gets assessed every three months for her medical and medications. She is happy and has made her home here. My sister likes visits and outings, but is happy to come back to Rainier School. She is treated by doctors and nurses who are familiar with DD folks and understand competency issues.
- P8:** Our daughter likes to go to our home, but after a day, she wants to return to Rainier School. Now she loves it here.
- P9:** In the outside community, medical people said that she needed to decide for herself, but she is not capable of that.
- P10:** My son is 25 years old. This is his second time at Rainier School. He was here two years ago and then tried placement in the community. When he returned (to RS) he was out of control and the community environment could not help him. There was massive property destruction - they just threw medications at him. Staff in the community program could not speak English well. We like the competent medical staff (RS) and our son is only on two or three medications now. He is happy and totally stable and has a

couple of jobs. He participates in activities. When he is home, he is ready to return to Rainier School. Staff care and are competent. It couldn't be a better facility. I'm glad our son is in an environment to keep him safe and which helps him to control his body. The community does not have legal authority because of various restrictions, and staff here can respond to difficult behaviors.

- P12:** I'm the mother of a 29 year old son who is 6'3" tall. In the community he would just walk into people's homes which often resulted in police involvement. I like the acreage here - my son needs space to move around. At a community (residential) option he had more restrictions. They tried different cottages and now he is happy. Rainier School respects his dignity. My son does not feel so closed in, and so he is not so desperate to get out. His medications are monitored. In the community he was on 12 or 13 medications, now it's only around four. My son has a job. The family lives in the Portland area and the proximity is good for the family. Everywhere else that my son lived before, he would ask when he was going to move. He no longer asks that.
- P13:** My daughter came in as a respite. She feels safe here. I appreciate the competency of the staff, especially medical. My daughter wants to move back to the community. It has been a complex process. After about 3 years of stabilized behavior, it is frustrating that no homes have been found for her.
- P4:** Four years ago my daughter tried community placement - it was a disaster. Those places are not what they say they are. Safety at Rainier School is a big plus. How things are engineered, the cottages, for example, have multiple staff. Staff can watch and monitor each other and keep accountable. Rainier School is safer, the cottages and grounds are safer. Rainier provides activities and social interaction. The lifestyle is more predictable. Those with autism need things to be kept steady for behaviors to be managed well.

Question 2: What is working well for your family member?

- P13:** It feels safe here. I appreciate the competency of staff, especially medical. In the community my daughter's hand was stitched without medication.
- P9:** My sister is offered choices at Rainier. Staff are good at letting her choose what to wear or what to eat. If she does not want to eat something, they do not force her.
- P13:** I like the continuity of care with little turnover and the stability of staff. She has been able to establish relationships with staff. Predictability!
- P12:** Medical people who are familiar with the developmentally disabled.
- P10:** Everything is working well; for example, the management of medications and the people he works with. He is happy, productive, and engaged. He enjoys people, likes the staff and others who live here.
- P9:** My sister spent 17 years in different homes and she finally feels safe. I like how things are set up and the staff accountability.
- P12:** I worked at Lakeland Village many years ago and it was horrid, like a warehouse. I didn't want that for my son. At Rainier School now, it's an amazing difference from that experience. Even the smell when you walk in - there isn't any.

- P8:** Group homes are seldom able to keep decent staff. The caring, or heart interest, is not in the group homes. Rainier has been able to deal with our daughter and her immense quirks. They find a way to work it out and she is making progress.
- P9:** My sister lived in the community for 15 years, then two different apartments. The staff were untrained and there were problems with background checks. Rainier is wonderful for all the reasons that have been stated. The community doesn't understand.
- P8:** Now, when I get a call, we don't panic. Rainier School staff ask for approval, our thoughts, and ask for input. The holds (restrictive) are legal. Staff know how to work with her - even the relief staff know her.
- P5 & P6:** Our daughter was at the Morgan Center, which didn't work, then group homes. She was in and out of the group homes before coming here. Crises occurred all the time. We couldn't get away for a vacation. She was taken to the hospital emergency room when in a crisis when they didn't know what to do. She has been at Rainier School for three years with no crisis!
- P6:** There is a difference between Rainier School and other facilities. There is good chemistry between the people who run Rainier and psychiatric and medical follow-through.
- P3 & P4:** Behavioral and psychiatric supports are working well. They have continual review of situations to improve on things. Other things that are working include safety, social interaction with her peers, and teamwork by all the employees. Our daughter is comfortable here and always ready to come back. We never had that before and that says a lot.
- P2:** My brother was in a nursing facility before. We expected safety, health, and happiness and it is good here for all of these. He calls home and lets us know what is going on. The medical staff are here on campus. They have an opportunity to see what is happening and get to know clients on a personal level. They recognized my brother's hip problem right away. Community care and hospitals were frustrating.
- P8:** Some agencies want to make a profit and let things slide.
- P7:** I was on a community board and they didn't have enough staff to fill the hours during the day. They ended up having to pay money back to the State.
- P11:** The coffee shop is working well! It's a wonderful thing to have.
- P9:** The staff enabled a visit to an important family member.
- P12:** Rainier is a stable environment that leads to stabilizing medications. Couldn't tell in the community.
- P10:** The medical staff is here and can immediately see what's happening.
- Question 3: Is there anything you wish was different or could be changed?**
- P2:** More outings would be nice. There are less problems when he's busy. He loves going out.

- P3:** There should be more activities, especially the pool. They should replace the staff who've been let go - it impacts outings and jobs.
- P4:** Stop the budget cuts. I would like to see more things/activities included (in the program), and more money to maintain the facility. I want to see the campus utilized better. Instead of closing, use the resources here.
- P5:** Our daughter is happy overall, although there could be more activities. It's hard to ask for more in this budget reality.
- P7:** I feel bad the pool was closed. They should not be cutting staff. It's the same with the bowling alley. There doesn't appear to be anything in the greenhouse. I would like to have an opportunity for our daughter to hear more music, such as concerts.
- P9:** All of the above. My sister had lots of therapy in the pool. I'm sorry that has stopped. More outings would be nice; miss the church services. She also liked to bowl.
- P11:** We have a small, specialized group of people (people with disabilities living in institutions) that is not well represented. I'm concerned about the political aspects. This is expensive real estate in a state that's broke. I would like to see more activities, like the pool, and I would like to believe the place (Rainier) will be open than just a few more years.
- P10:** This is a special place for this population. You can't replace Rainier School - can't replicate it, it will not happen. Rainier is a great resource, underutilized. This population isn't using all what Rainier has to offer. Sending this population out (to the community) is not the solution. Shut some (other RHCs) down and bring to Rainier those who cannot be placed in the community.
- P5:** Remember trips to the emergency room are very costly. I wrote to my representative that they should shut the other RHCs and expand Rainier School.
- P4:** Costs are dispersed in the community. Police, jail, hospital, and court costs are not completely included in (cost comparison) studies. Medical costs (in the community) must be astronomical.
- P12:** Need realistic budgeting. In the community there is subsidized housing, etc. You need a realistic evaluation of what is really the cost of Rainier School vs. the community. I would like to see the swimming pool and bowling alley, better dental care, and a healthier diet with less processed food.
- P10:** We've all said we feel better about safety here. That's a cost, too.
- P13:** I respectfully disagree that there is not a community solution. My daughter wants to live in the community. She doesn't have the opportunities to contribute to the community that I want (her to have) and she has a legal right. I want the community to learn from her, too. The bottom line is that it is a personal choice that should be honored. Why it is an either or? Why aren't there internships here, such as recreation and art therapists? We need to be creative and have a more therapeutic approach vs. the behavioral management approach. I'm distressed that the cut back of staff has been detrimental and is bad for morale. Nutrition has been affected by the budget cuts and nutrition plays a role in behavior. I would like Rainier School to be used as a transition place - respite could be like a bridge from here to there. The state needs to make a commitment to holding community programs to the same regulations as Rainier School which are: 1)

staff accountability; 2) staff training; and 3) medical services. May have to pay more for services in the community. My daughter wants placement, cries every weekend. She does not have a choice if there is not competent care available.

P4: Did you choose Rainier School?

P13: My daughter was with a community program for 3 ½ years before she came here as a respite. Not forced, but there was no other option. She wants to be in the community. It is the lesser of two evils.

P4: Our daughter thinks Rainier School is the community.

P13: Need competent care in the community.

P12: I wish it was a perfect world with lots of good choices. I wish you could have whatever works. Would hate for this (Rainier School) to be shut down.

P9: Providers in the community are mostly for profit.

P6: Non-profits want more money for salaries, etc.

P11: Most people are not here against their will.

P13: I don't agree that it is all about profit in the community. *[At this point Participant 13 felt as though they were in the minority opinion and chose to leave the focus group.]*

P11: If our son could be in the community, we would want that. This (Rainier School) is very valuable property that other people want. The community doesn't have resources; people don't want to commit the resources. We have to impress on decision makers how this resource could be used.

Question 4: What does it take for you to trust that community programs can support your child?

P2: They would have to prove that they could keep him happy, healthy and safe. My brother was in a nursing home in the community and their solution was to give him more drugs.

P3: I've lost my trust! There is nothing they can do to regain my trust.

P4: We are very involved with our daughter and were truthful about her needs. The community promised numerous times. The community was good about selling themselves to us and it sounded good. But the fact is, it was a horrible situation for our daughter and for the whole family. While in placement from home, within two weeks, our daughter was in jail for seven days. This is not an uncommon experience.

P12: I was given a choice of lock down vs. jail for my son.

P4: The community is not providing for the most needy very well.

P5: I can't think of placing my daughter out of Rainier School into the community. I couldn't go through it again to pick up the pieces.

P6: Same as my wife (P5). The sheltered workshop was good, but that ended. The home situation wasn't good. They would have to triple the budget and pay employees

probably twice what they get now. Psychiatric and medical in the community would need to improve.

- P7:** Medical supervision would need to be controlled. Would need a safe/stable living environment with trained.
- P8:** I don't see the coordination in the community. We have numerous people who need jobs. Businesses are not going to hire a DD person when so many people need work. Staff need more education. There would have to be more coordination and cooperation.
- P7:** The sheltered workshop is no longer there. I don't think my daughter could have a meaningful job.
- P8:** How many businesses can hire a person with developmental disabilities?
- P9:** I could not trust EVER - no way! There are many community placements where people are overdosed. After 15 years, my sister moved into my home. I did not qualify for respite and was worn out. The case manager was impossible to deal with. The whole process was horrid. My sister was sexually and physically abused. No way!
- P11:** Ditto. It's like there are two different cultures and its survival of the fittest. I'm a survivor, but my son isn't. The people in charge (Rainier School) have a great deal of experience. For people who work here, every day is an education for them. Most people aren't trained to cope with the needs. We need to focus on what's working.
- P12:** If I were to place my son, it would have to be a religious-based community where it is a vocation; they would treat him with dignity and respect, and value him as a gift. My son was beating me up and our lives were in danger. DDD threatened to put him in a homeless shelter if we didn't come get him. There were problems between bureaucracies. Here, it's a smaller community with less bureaucracy. At Rainier, they don't have to go through so much red tape. The nature of a bureaucracy is that it is hidebound, forgetful of the people they are supposed to serve.
- P4:** In the community my daughter lived close to town and all the stimulation got her into trouble. The community is not accepting. People (with disabilities) can be themselves here and be totally safe.

Question 5: How could institution workers help people in the community?

There were no comments to this question.

Question 6: Looking into the future, if you could have three wishes for your son/daughter/relative, what would they be?

- P12:** For my son to stay alive - looking at politics and quality of life; that he could live on a farm with lots of space; and that he could be part of a religiously-based community with dignity and respect.
- P9:** I'm very fearful about euthanasia. Health, happy, and safe.
- P8:** Happy, healthy and safe.
- P7:** To be healthy medically; socially healthy (like going to the coffee shop); and happy with her job. She loves Rainier School and it is her home.

- P8:** I used to run a camp for special needs. It was a real challenge with great rewards. You could use this big campus.
- P6:** Safe, healthy and happy.
- P3:** That there was no threat of closure, that she would be happy, and that there was peace for our whole family.
- P2:** I agree with the others. I think you should open up the facilities that have been closed. There needs to be more to do Rainier School.
- P8:** I was very active with the Kiwanis. They had a pony club which was very therapeutic. They need that here - very therapeutic.

Question 7: Wrap-up: Is there anything else you would like to add to our discussion today?

- P4:** I went to Olympia and saw all the committees not working together. I see other uses at this campus and it would be more efficient if we could all work together. So many groups are trying to get the same dollar. It's not benefiting either one; there must be a better way to work together.

**GROUP 12:
FAMILIES OF LONG-TERM (OVER 20 YEARS) RESIDENTS
(LAKELAND VILLAGE FOCUS GROUP NOTES)**

April 15, 2010

Question 1: What services does your family member currently receive?

- P1:** Full time care, constant supervision due to moods.
- P6:** Everything there is to offer; I'm pleased with Lakeland Village shopping trips. He goes on rides on good days. He trains the staff.
- P3:** Very dependent; has full team (that is, psychology, speech); needs help with everything; earns money at work to get a sense of accomplishment. Lakeland is a good place for him.
- P5:** My daughter has full time care in the nursing facility. She came from Interlake School. She is treated normally, staff take her shopping and to the community. Staff have come on their days off to take her out. The staff are fantastic!
- P8:** My daughter has been here 38 years. She has medical concerns. She teases with staff, carries her own belongings, and has a key to her room. She has used all the services Lakeland provides except for behavior management.
- P9:** I'm a retired R.N. from Lakeland Village and I want to deviate from these questions to speak my mind. I feel like this (focus group) is politically motivated and financially driven. I have invited Olympia to come to Lakeland to see that our clients are not able to live in the community. Even community resources like hospitals can't provide the necessary care for our people or people with developmental disabilities. Our nursing facility is under federal care with 1:1 and 2:1 medical care.
- P5:** Why can't we cut to the chase and get to the point. We are wasting time.
- P10:** Speech and physical therapy; occupational therapy with adaptive equipment; a dentist who knows our clients and won't refuse them because they are on Medicaid; RNs; and maintenance of equipment.
- P11:** There's only one Lakeland and they are doing a wonderful job of serving the clients and they love the children.
- P6:** Amen!
- P9:** Staff grows with knowledge and understanding of the nuances.
- P8/P3/P5:** Comforted by the oversight of their family member by extra staff and surveyors because most of their family members can't speak for themselves.

Question 2: What is working well for your family member?

- P9:** My daughter has only one functioning lung. She was treated at a community hospital which suggested hospice and sent her back to Lakeland.

- P8:** My daughter had hip replacement and her shift charge went to the hospital to stay with her after surgery.
- P10:** My brother is on hospice, but Lakeland staff have taken such good care of him; he's still thriving. He would be dead if he lived in the community.
- P6:** Good coordination with the hospital and Lakeland. The Lakeland doctors followed him closely through nursing care on Rosewood at Lakeland Village.

Question 3: Is there anything you wish was different or could be changed?

- P3:** It would be working well if Central Office would quit running Lakeland Village like its being closed. It's all money related and politics. These are vulnerable citizens of Washington State. Take care of your disabled, we have to!
- P9:** Quality of life views differ with legislators, Central Office, and consumers of LV services.
- P10:** Not everyone will make it in the community and not everyone will make it at Lakeland. We need to quit arguing. The day my brother moved to Lakeland was the worst day of my parents' lives and it was the best day of my brother's life.

P6 P3/P9: Agreed.

- P11:** We were on a waiting list for 10 years before our child was admitted by court order.
- P5:** Should have Lakeland Village staff accompany clients to the hospital during stays. This used to happen, now money driven.

Question 4: What does it take for you to trust that community programs can support your child?

- P1:** I don't know about community programs.
- P10:** If you can't care for the 39,000 (referring to caseloads), send them here.
- P3:** Open Lakeland and admit more from the community.
- P9:** Clients are not disposable.
- P10:** Clients are people, not numbers!
- P9:** We don't have quality assurance and close monitoring in the community. They need staffing and training. I've seen SOLA clients in the community on anticonvulsants going to pubs and looking disheveled.
- P8:** DSHS has to prove to us that we can trust them. To follow through on promises in realistic amount of time, not years.
- P6:** Close supervision of my son. He would be run over by a car in the community. Safety issues are handled here.
- P9:** The community isn't working because people end up here on respite. There are people who can't be cared for in the hospital, so Lakeland Village gets the ones that can't make it in the community, jail, or Eastern State Hospital's psychiatric ward.

- P5:** Lakeland Village's nursing facility is ten times the facility I would get from a nursing care center in the community. The quality of nursing care is so much better.
- P3:** There is less staff turnover at Lakeland Village vs. the community where they only get minimum wage. The turnover is big time in the community.
- P5/P6/P3:** Nothing in the community could earn my trust.
- P11:** We live in a small town. There are lots of nursing home groups full of all types of disabilities. All they do is sit.
- P8:** Lakeland is a community in itself and it is home.

Question 5: How could institution workers help people in the community?

- P9:** We don't mind taking respites, but we are allotted no extra staff for this. When a dangerous client or resident comes, we need 2 or 3 more people to help. Lakeland never gets paid for this.
- P3:** I would like to see Lakeland services expanded for medical, dental, vocational, PT, etc., because we know how to provide care. Most people with developmental disabilities in the community have no jobs. I would like to see more education in the community about what Lakeland really is - it's not a place for warehousing.
- P10:** DSHS should provide education to the public about Lakeland Village and what we provide here as well as teach about disabilities.
- P3:** Don't like institutions whether good or bad. People need to learn the good.
- P5:** People equate with warehousing which isn't true.
- P9:** The training here is about all the diseases that DD people can have and we watch for it.
- P5:** All of us could invite people to an Open House.
- P8:** Legislators have visited Lakeland and their talk has been sympathetic. Once they leave they say, "I would never have guessed what a wonderful facility LV was." They would never have known (without a visit).

Question 6: Looking into the future, if you could have three wishes for your son/daughter/relative, what would they be?

- P10:** Keep Lakeland open - if it ain't broke, don't fix it. My brother is perfectly happy here.
- P8:** More staffing to do things and keep Lakeland open.
- P6:** Bring back the social workers!
- P9:** Parents fear that when they are gone that no one will advocate to keep their family members here. There is security in knowing that they will be cared for after we're gone.
[Universal wish]
- P5:** Keep Lakeland Village open with more staff.

P3: Don't reduce Lakeland, expand it.

P1: Put more people here, fill it up.

P11: Keep Lakeland Village open.

Question 7: Wrap-up: Is there anything else you would like to add to our discussion today?

P10: The DSHS Secretary is coming on the 28th at 4:30 pm. Why can't she come during the day to see Lakeland in full swing when the clients are in full action? She won't see anything going on.

P8: Send the DDD Director and other Olympians to see Lakeland. More people in the hierarchy need to get out and see the RHCs.

P2: I can't understand why more people didn't come for this today.

P9: All RHCs are very different. Yakima Valley School, Rainier and Fircrest: vast differences. I hate to compare them, even case management is different. Lakeland Village training is totally different that community when it comes to Federal regulations - not systemized.

P10: Institutionalization was the best and worst day of my parents' life. In my nephew's case, if Fircrest wasn't there to help, who would, where would he be?

P6: I suggest having the superintendant and/or a state representative here at these focus groups to get more listening power and authority, so we can hear from the horse's mouth.

P5: It's unsettling to see this meeting because it's like the Davis/Deshay group meeting we paid \$ 500,000 for.

P3: If this meeting's minutes are heard - let them reflect what we said. Not like the Davis/Deshay group - no one listened. This group is saying the same thing. The legislative session was all about closing RHCs.

Governor
Chris Gregoire

2010 POLICY BRIEF

REFORMING HOW WE CARE FOR WASHINGTONIANS WITH DEVELOPMENTAL DISABILITIES

Governor Gregoire believes many persons with developmental disabilities are best served in integrated community-based settings rather than in the state's large institutions for the disabled, called residential habilitation centers. The Governor believes this is especially true in the case of children, who are better served in small homes near their local schools.

A study ordered by the 2009 Legislature found that Washington serves proportionately more people in institutions than most other states. The Governor finds this proportion unacceptable and agrees with the study's conclusion that reforms are needed to increase the number of clients who receive integrated care in the community.

Not only does the Governor believe many citizens with developmental disabilities would be better served in communities than in habilitation centers, she also recognizes that reforming how we care for these citizens will free up badly needed funds to extend better care for more clients. She supports making long-term investments to gradually build a system of integrated community-based care to deliver better service.

Governor Gregoire proposes to:

- ❖ **Close two of the state's five Residential Habilitation Centers.** In the early 1970s, six state centers served more than 4,000 residents. Today, five centers serve 900 long-term residents and contain many underused buildings. Governor Gregoire proposes closing the Frances Haddon Morgan Center in Bremerton and to begin the downsizing of Rainier School in Buckley by June 2011, with a target closure date for Rainier of June 2014. Residents of these facilities would be carefully transitioned to new residential settings in the community or in one of the remaining centers. The Governor proposes to fund 60 new community-based residential slots in Fiscal Year 2011.
- ❖ **Retain expansion of the Children's Intensive In-Home Behavioral Support program.** Despite the state's current budget difficulties, Governor Gregoire proposes that this vital program continue to expand behavioral management intervention services to more children and their families, up to the limit of 100

families approved by the federal Centers for Medicare and Medicaid Services, to prevent out-of-home placements.

Maintains \$3.7 million in state funding and \$4.6 million in federal funding.

- ❖ **Create new programs for children.** Current private providers have limited expertise and capacity for serving children in community-based settings. Governor Gregoire proposes to supplement private provider capacity by creating three new State-Operated Living Alternative facilities specifically for serving children before June 2011.

Appropriates \$345,000 in state funding and \$407,000 in federal funding.

- ❖ **Create community-based residential respite capacity in each region.** Many families seek respite services from the habilitation centers because limited numbers of providers are able to appropriately deliver respite care in home or community-based settings. Governor Gregoire proposes to create two community-based respite slots for each of the six regions, beginning next year.

Appropriates \$1.8 million in state funding and \$2.3 million in federal funding.

- ❖ **Expand funding for community-based residential services.** The 2009 Legislature provided funding to grow the Expanded Community Services and the Community Protection Services programs so individuals who need safe homes have community-based residential options. The Governor proposes to expand these services and programs to serve more clients, adding 24 slots for Expanded Community Services and 13 more slots for Community Protection Services.

Appropriates \$2.0 million in state funding and \$2.6 million in federal funding.

- ❖ **Increase staff temporarily to support institutional clients transitioning to community living.** Governor Gregoire proposes funding eight new positions at the Division of Developmental Disabilities to provide transition planning, resource management, case management and quality assurance services to help institutional residents relocate to community living.

Appropriates \$580,000 in state funding and \$515,000 in federal funding.

Governor Gregoire understands the importance of state support to families and clients with developmental disabilities, and of the need for a continuum of services, from in-home care to community settings to remaining in institutions. The Governor is determined to implement smart reforms in how supports are provided in order to benefit clients, offer services to more citizens and reduce costs.